

National Institute on Drug Abuse

# **Integrating Cultural, Observational, and Epidemiological Approaches in the Prevention of Drug Abuse and HIV/AIDS**





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# **Foreword**

This critically important volume, published nearly two decades after the human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS) epidemic began, provides both a historical and future perspective on the evolving substantive and methodological dialog between epidemiologists and ethnographers who focus on risk behaviors, HIV transmission, and strategies to prevent further spread of the infection. Emerging from this ongoing dialog is an integration of quantitative and qualitative approaches for the collection, analysis, and interpretation of data about hard-to-reach, high-risk, drug-using populations—an integration that has helped us better understand risks for HIV that result from behavioral transactions in the processes of drug acquisition, preparation, and injection in public and private settings. Combining ethnographic and traditional epidemiological methods in the study of drug use and HIV/AIDS has informed our knowledge of the microlevel and macrolevel factors that influence the behavioral transactions of drug users and place them at risk of acquiring or transmitting HIV and other blood-borne infectious diseases. This has resulted in the development and testing of better, more effective, and different interventions to reach out-of-treatment injection and noninjection drug users and enable them to reduce their risk behaviors and prevent the spread of new infections.

The history of support by the National Institute on Drug Abuse (NIDA) for ethnographic and anthropological research on drug abuse and HIV/AIDS parallels the scope and magnitude of these interrelated epidemics. Early in the HIV epidemic, enumeration of risk behaviors was necessary to understand the extent of the infection, assess its potential for transmission, and target interventions most effectively. As the epidemic evolved, however, more needed to be known than enumeration alone could provide about the context of risk, that is, about the situation or circumstance in which risk behaviors occur. It became clear that the theoretical and methodological dialog that had begun between epidemiologists and ethnographers offered a unique research paradigm for examining the nonrandom patterns of risk behaviors related to drug use, HIV transmission, and the contextual factors influencing these behaviors. Traditional anthropological methods and research designs are now viewed as essential complements of epidemiological approaches in

HIV prevention research, largely because of their critical role in identifying and understanding the interactions among contextual and environmental factors, drug abuse, and the spread of infectious diseases. Anthropologists and epidemiologists have collaborated for years in studies of drug abuse. The need for such cross-disciplinary collaborations has become more evident over the course of the drug abuse and HIV/AIDS epidemics, not only because their interrelationships have become increasingly complex but also because we are now seeing an epidemiological synergy of drug abuse, HIV/AIDS, and other serious blood-borne diseases (such as hepatitis B and C viruses). Rates of co-occurring infections are increasing among drug users—a dynamic that has immediate implications for potential transmission to others with whom drug users have contact, whether by shared use of syringes and other injection equipment or by unprotected sexual contact.

As part of the ongoing effort to facilitate a methodological dialog between epidemiologists and ethnographers for HIV prevention research in drug-using populations, NIDA and the American Anthropological Association's (AAA) Commission on AIDS Research and Education, with support from the Wenner-Gren Foundation for Anthropological Research, cosponsored an AIDS research and education conference in Washington, DC, in fall 1996. The conference sought to review the current status and future prospects of "integrating anthropological approaches in epidemiological and prevention research on drug abuse and HIV/AIDS." On behalf of NIDA, the AAA's Commission on AIDS Research and Education, and the Wenner-Gren Foundation, we would like to acknowledge the anthropologists, ethnographers, and epidemiologists in the field of drug abuse and HIV prevention research who gave presentations at the conference. In particular, we are grateful to the volume editors—Drs. Patricia Marshall, Merrill Singer, and Michael Clatts—for their important editorial efforts and other contributions in making this volume possible.

The 11 chapters in this volume contain the essence of the conference presentations. These include the application of ethnographic and other qualitative methods in epidemiological research on drug use and HIV/AIDS in diverse community settings; the significance of historical, political, economic, and sociocultural factors in understanding drug use behavior and risks for HIV/AIDS; the integration of methodological approaches in collaborative studies involving ethnography and virology; the challenges that often arise

in ethnographic and epidemiological research on drug abuse and HIV transmission, such as studies of social and sexual risk networks, needle exchange programs, gender-based and other sensitive issues, and violence; the role of multidisciplinary and qualitative research in developing treatment and prevention strategies and evaluating interventions; and the nature and resolution of ethical dilemmas in anthropological and epidemiological research on drug abuse and HIV/AIDS.

The intervening years since the conference have taught us more about drug use, HIV/AIDS, and the emergence of co-occurring infections like hepatitis B and C. But the epidemic of HIV/AIDS is clearly not over. Injection drug users represent more than 50 percent of all new infections in the United States today. We anticipate that NIDA's HIV research portfolio will continue to support ethnographic and epidemiological studies and to challenge the field to integrate and apply concepts and methods from different disciplines. The ongoing theoretical and methodological dialog between traditional epidemiology and ethnography continues to inform and advance the science of HIV prevention research. However, there is much more to be done. We are challenged to do our research differently, do it more quickly, and most of all, do it better.

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# **Chapter 1. Introduction: Frontiers in AIDS and Drug Abuse Prevention Research—Toward the Integration of Anthropological and Epidemiological Approaches**

*Merrill Singer, Patricia Loomis Marshall, and Michael C. Clatts*

## **ABSTRACT**

This chapter explores the nature of ethnography as a research methodology, its demonstrated contribution to AIDS prevention research, and the potential value of expanded collaboration between anthropologists and epidemiologists in combating AIDS. A central goal of the chapter is the examination of six theoretical assumptions that together constitute the core paradigm of anthropology and help explain the unique relationship between the discipline and the ethnographic approach to knowledge production, namely, the belief that the social whole is more than the sum of its individual members, change is ubiquitous in human social life, context is a powerful influence on human behavior, social worlds are complex and intertwined, meaning is a central feature in human experience and behavior, and a critical gap exists between every cultural ideal and the reality of day-to-day life. On the basis of an acceptance of these assumptions, anthropology seeks to understand the social nature of human belief and behavior. Consequently, in HIV prevention research, anthropology is concerned with developing approaches for social-level intervention. This orientation presents a significant contrast to traditional individual-level epidemiological approaches. Collaboration between anthropologists and epidemiologists, with the intention of building multilevel research and intervention models, offers an important arena for improving the efficacy of HIV prevention efforts.

Key words: Anthropology, ethnography, epidemiology, drug abuse, prevention research

## BACKGROUND

With the intention of dramatically conveying the urgent status of the global acquired immunodeficiency syndrome (AIDS) pandemic, several years before his untimely death, Mann and colleagues introduced their book *AIDS in the World* with a grim question: “The course of the pandemic within and through global society is not affected—in any serious manner—by the actions taken at the national or international level . . . As we enter the second decade of AIDS, it is time to ask: Is the AIDS pandemic now out of control?” (Mann et al. 1992, p. 1).

At the same time, there have been recent moments of enormous hope and keen excitement even among battle-weary veterans of the AIDS struggle. Whispers of cure remain in the air, whether warranted or not, and the development of an AIDS vaccine continues. With AIDS, in short, it always seems as if we are at a crossroads, always approaching a moment of promise, while simultaneously recognizing the rising levels of human immunodeficiency virus (HIV) transmission and human suffering among certain populations. In that we never seem to know just where we are with the AIDS epidemic—Is this the end of the beginning, the beginning of the end, or somewhere in between?—AIDS is aptly called “the first postmodern epidemic” (Fee and Krieger 1993).

As anthropologists involved in AIDS research, prevention, and education, the contributors to this research volume are concerned with identifying ways in which our discipline can make a more useful contribution to the fight against AIDS. The “anthropology of AIDS,” if such a thing can be said to exist, is now well over a decade old. Clatts and Gorman were the first anthropologists to do work on AIDS; the earliest anthropological writing on the epidemic was by Feldman in 1985. Ironically, in the first volume edited by anthropologists about AIDS (Feldman and Johnson 1986), most of the individuals who authored articles were sociologists. As Bolton and Orozco have observed, “In the early years of the pandemic, anthropologists were slow to respond to this rapidly emerging health problem. After the mid-1980s, however, this initial neglect was followed by serious engagement with the epidemic on the part of a large number of anthropologists” (Bolton and Orozco 1994, p. vi).

In 1994 Bolton and Orozco compiled a bibliography of more than 1,500 publications and conference presentations by anthropologists

and others with a related perspective. This figure—which would be far larger if calculated today—indicates the significant attention AIDS now receives within the discipline. As the number of anthropologists working in AIDS has grown, there has been a considerable diversification in the research problems they have tackled and in the number of ways they have contributed to AIDS work. In studies of AIDS and drug abuse, anthropologists have been—with unparalleled support from the National Institute on Drug Abuse (NIDA)—particularly prominent. But have anthropologists made a difference in understanding or responding to AIDS?

It is the sense of the contributors to this volume that this question can be answered in the affirmative, although none would argue that the “difference” anthropology has made is adequate. Very likely, anthropology’s most notable impact has been in the area of methodology. In the arena of public health, ethnography without question has found new relevance in the era of AIDS.

## **ETHNOGRAPHY AS METHOD AND THEORY IN ANTHROPOLOGY**

Ethnography commonly is seen as the sine qua non of anthropological study. Indeed, the connection between ethnography and anthropology is of such tremendous importance that it is often not recognized that many anthropologists—including those who specialize in biological anthropology, linguistics, and archaeology—never do any ethnography at all. Among cultural anthropologists, however, not to have done ethnography at all is tantamount to not being a real anthropologist in the eyes of many members of the discipline.

Yet, no discipline consists of just a method, however much at times it has seemed easier to define anthropology by its special approach to data collection than by the shared frameworks of understanding that drive its research program. Contrary to the common assertion that methods are theoretically neutral strategies for the gathering of empirical data (Pelto and Pelto 1990), it is our sense that ethnography is predicated on a number of fundamental assumptions about the subject under study. If we accept these assumptions, as almost all anthropologists do, then ethnography makes sense as an appropriate and useful technique for learning about essential aspects of the human world.

Ironically, nonetheless, to this day ethnography remains an underdefined concept. Used to label both a process and a product (Agar 1996a), the term eludes a uniform definition. As a process, ethnography has been described as an approach to research in which the researcher “closely observes, records, and engages in the daily life of another culture . . . and then writes an account of this culture, emphasizing descriptive detail” (Marcus and Fischer 1986, p. 18). However, it is not clear that for a research project to be called an ethnography the investigator must be from a different culture than the one under study. Ethnographers have conducted studies in their own cultures for at least the past 60 years (Goldschmidt 1947; Henry 1963; Powdermaker 1939) and even more frequently in recent years (Arens and Montague 1981; Burawoy et al. 1991; Spradley 1975).

The term “ethnography” is used in this volume to refer to firsthand, immersion-based research that is conducted in natural settings in which the researcher directly observes and, at least to some degree, participates in the everyday lives of members of the group of concern. The term “natural settings” is used in contrast to laboratory or other social space that is constructed and to some degree controlled by the researcher. In the arena of drug abuse and AIDS research, this has led to studies on street corners and back alleys and within shooting galleries, crack houses, and prostitution stroll areas, a body of work that rests on a prior history of ethnographic street drug use research (see Singer, this volume, “The Ethnography of Street Drug Use Before AIDS: A Historical Review”). Unavoidably, participation in the social worlds and activities of the people under study is conditioned by local circumstances. In a study of an illicit drug shooting gallery, for example, the ethnographer is not expected—on health, legal, and ethical grounds—to inject drugs, although there is certainly a long tradition of anthropologists sharing mind-altering substances as participant observers of indigenous drug taking in a variety of cultural settings (Singer, this volume, “Toward a Critical Biocultural Model of Drug Use and Health Risk”). Participation in some situations may be limited to sharing casual time with members of the group under investigation; in other settings, much more extensive participation may be possible. Often, ethnography entails “a dialectic process that cycles back and forth between assuming the role of a participant and the role of an observer” (Carlson et al. 1995, p. 13). The key element is that the ethnographer gains sufficient access to a group to observe and record life as it occurs naturally, as opposed to merely interviewing people in artificial settings constructed or adopted for the purposes of research.

While the potential value of this approach for gaining insight into the nature and determinants of human behavior seems evident, the full embrace of ethnography is predicated on six theoretical assumptions that could be said to constitute a core paradigm within anthropology. Each of these assumptions will be examined in turn.

### **The Social Whole Is More Than the Sum of Its Members**

First, inherent in the ethnographic approach is the assumption that the social whole is more than the sum of its parts, more than the total of its individual societal members. In addition to the individuals, there are the social relationships that bind individuals together in complex structures of exchange, communication, support, and differential authority and power. As Lincoln and Guba (1985, p. 105) stress, “Human beings are always in relationships . . . One cannot study people without taking these relationships into account.”

Consequently, since the mid-1980s a growing number of researchers have incorporated network concepts into the study of health issues (Friedman et al. 1999; Koester and Weeks 1999; Singer 1985). This work emerged from the recognition that focus on the individual as the primary driving force in behavior is restrictive and fails to account for broader patterns and trends (Auerbach et al. 1994; Friedman 1993; Sterk-Elifson and Elifson 1992; Taylor 1993). For example, in an extensive study of network factors and HIV risk in Colorado Springs, almost 600 primary respondents were interviewed concerning health, risk, and network variables. Through this approach, a large network consisting of a well-connected core component and numerous marginal subcomponents was identified. HIV-positive persons were found, for the most part, to be isolated in the smaller subcomponents of the network, whereas those HIV-positive individuals located in the central component occupied noncentral network roles. This important finding was used to explain the low level of endogenous HIV transmission in Colorado Springs (Rothenberg et al. 1995). Conversely, in a study of an HIV high-prevalence area, HIV-positive persons were found frequently to be in the core network component rather than in peripheral components (Friedman et al. 1999). Ethnography, which commonly has been used to trace patterns of social relationship (e.g., kinship structures), presumes that if we are to understand social behavior, we must simultaneously understand the actual nature and functioning of the “on-the-ground” relationships that abide among actors and not just the ideas, attitudes, and intentions that they express during office-based, structured survey interviews.

## **The Ubiquity of Change**

Second, ethnography, especially as it has been practiced since the Second World War, assumes that sociocultural systems are dynamic; in large and small ways, things are constantly changing along both cyclical (e.g., seasonality) and noncyclical (e.g., innovation, social evolution, social transformation) pathways. Ethnography, with its traditional emphasis on ongoing data collection and prolonged contact, prepares the researcher to expect change and allows her or him to monitor it. Put simply, ethnography presumes “the ubiquity of change” (Herskovits 1945, p. 144). State-of-the-art street drug use studies, for example, consist of prolonged, community-based observational tracking of significant changes in drug preferences, drug use patterns, drug availability, methods of consumption, and associated HIV, sexually transmitted disease, tuberculosis, hepatitis, violence, and other health risks (Singer, *in press*). This approach is significant because, as Inciardi and colleagues (1993, p. 1) correctly note, “If anything has been learned from the history of drug use in America it is that ‘drug problems’ are ever-shifting and changing phenomena. There are fads and fashions, rages and crazes, and alternative trends in drugs of choice and patterns of use.” In a similar vein, Ouellet and coworkers (1995) discussed the dynamic elements of illicit drug use, noting the continual fluctuations in the popularity and availability of particular types of drugs. Critical focus in the monitoring of such change is on situations that Mead (1999) referred to as “points of divergence” in the flow of social processes, that is, situations that have potential for producing change in preexisting stabilities. For example, the development of crack cocaine and its street-level social marketing by drug dealers had an enormous impact on drug use patterns, social relationships among drug users, and the health of those caught up in the “crack life” (Carlson and Siegal 1991; Ratner 1993).

## **The Importance of Context**

Third, ethnography assumes the fundamental importance of context (Singer et al. 1992). As Lincoln and Guba (1985, p. 39) note, “Realities are wholes that cannot be understood in isolation from their contexts, nor can they be fragmented for separate study of the parts . . . because of the belief that the very act of observation influences what is seen . . . research interaction should take place with the entity-in-context for fullest understanding.” Beyond immediate social settings and social networks, the context of human behavior extends socially across class, gender, ethnic, or other life-shaping relationships. Although in

the past ethnographers often tended to narrow their attention to local behaviors in microcontexts (e.g., individual villages or neighborhoods), in the highly intertwined global community we all inhabit, a world in which AIDS quickly became an international pandemic, it is widely recognized that although ethnographers do best when they keep their feet firmly planted on the ground, it is critical that they look beyond the narrow boundaries of local settings (Farmer et al. 1996; Singer 1997a).

### **Social Complexity**

Fourth, ethnography engenders a profound appreciation of social complexity, including previously unknown aspects of social behavior. At present, there are no “complete” descriptions of any behavior; there is always more to learn. Consequently, in social research there is considerable opportunity for new discovery. However, some research approaches are more open to discovering the unexpected than are others. Ethnography, as a form of naturalistic inquiry, is a highly porous approach that imposes little in the way of researcher control over the field of study. In sacrificing control, a capacity that allows researchers to focus narrowly on specific relationships of interest, ethnography gains in serendipity, including discovery of patterns or relationships that are outside the awareness of and hence are not self-reported by research subjects or even previous researchers working in the same area of study. It is this feature of ethnography that, for example, led to the recognition that injection drug users (IDUs) primarily “share” their injection equipment because of a lack of access to sterile syringes rather than because of a ritual need to build social ties through syringe-mediated communion (Inciardi and Page 1991; Koester 1994). Ultimately, this insight led to a reformulation that characterized multiperson syringe use not as an act of reciprocal sharing but as a desperate adaptation to scarce resources (Carlson et al. 1994).

### **The Subtlety and Complexity of Meaning**

Fifth, ethnography attunes the researcher to the realization that in dealing with humans, there is always the inescapable issue of meaning. Taking an example from Ryle, Geertz (1977, p. 6), for example, summarizes the issue well by noting that “the difference, however unphotographable, between a twitch and a wink is vast; as anyone unfortunate enough to have had the first taken for the second knows.” The difference, of course, is communication. The twitch means nothing; it is an uncontrolled, perhaps unconscious behavior.

The wink, by contrast, means a lot, although just what it means is different in different contexts—from a sign of agreement, to a signal welcoming participation in a playful trick, to an invitation to another kind of playfulness that AIDS and sexually transmitted disease researchers customarily refer to as “risk behavior.” As this example suggests, data collection that ignores the role of meaning in human affairs, that is, data collection conducted without adequate contextual awareness, risks substantial misunderstanding. Nonethnographic quantitative methods are at special peril in this regard. In the arena of illicit drug use, where falsification is a well-honed survival strategy, failure to attend to the frames of understanding that underlie self-report can be disastrous (Bourgois 1996).

Social life, in short, is a never simple or straightforward. Rather, it is a complex but meaningful dance between the light and the shadows, intended to reveal some things and to conceal others, not only from the “audience” but also from the “actors.” Ethnography seeks to comprehend the full complexity of social life, including those things that are most hidden and, hence, most revealing.

### **The Gap Between the “Real” and the Cultural “Ideal”**

Sixth, despite a fundamental concern with the insider’s perspective and unique understanding of reality, ethnography presumes a gap, of potentially monumental proportions, between the favored “ideal” and the observable “real,” including differences between what people say they do and what the ethnographer sees them do. Three examples from HIV prevention research are illustrative. In her study of male clients of female prostitutes in Camden, NJ, Leonard (1990) found a notable inconsistency between clients’ self-reports of risk avoidance and their actual behavior in preparation for sex with a prostitute. Leonard interviewed 50 men, 20 of whom said they had used a condom during their most recent sexual encounter with a prostitute. Although all of the men whom she interviewed were out seeking a sexual encounter, and had stopped her on the street assuming she was a sex worker, only 3 of the 20 were in possession of a condom at the time of the interview. Similarly, in studies of IDUs in Miami, FL, ethnographic observations have failed to confirm self-reports of regularly obtaining new needles before shooting up or of always avoiding shooting galleries. Individuals who denied shooting gallery experience during structured interviews later have been observed injecting drugs in galleries (Page et al. 1991). A final example can be found in Bolton’s (1992) study among gay men in Belgium. As he

notes, “On the basis of surveys that had been done, it was concluded that gay men in Belgium knew how HIV is transmitted and that they had changed their behavior sufficiently to make it unnecessary to expend further efforts on AIDS education and prevention in that segment of Belgium society” (Bolton 1992, p. 134). However, Bolton’s participant observation in the gay community of Brussels (up to the point of actual HIV risk), including allowing himself to be picked up in gay bars and taken home by his date, convinced him that “unprotected anal intercourse was still widely practiced, as were unprotected oral sex and rimming” [oral/anal stimulation] (Bolton 1992, p. 135).

In summary, it is fair to say that ethnography is not a merely a neutral research method, in that it is not so much a technique for data collection as it is a full methodology for approaching and understanding the subject of social science research. In other words, ethnography weds methods of data collection (e.g., participant observation, informal interviewing, structured interviewing, ethnosemantic elicitation, network analysis) with implicit theories about human behavior and social life.

## **ANTHROPOLOGY AND SOCIAL PREVENTION MODELS IN DRUG ABUSE AND HIV/AIDS**

This discussion raises the question, What has been the impact of anthropology’s approach to understanding AIDS and drug abuse prevention research? It was precisely this concern that gave birth to this volume. Until relatively recently, AIDS prevention research has been dominated by a set of psychological models of motivation and behavioral change, including the theory of reasoned action (Azjen and Fishbein 1986; Fishbein and Azjen 1975), the health belief model (Becker 1977; Janz and Becker 1984), and self-efficacy theory (Bandura 1986, 1992). These approaches have tended to focus attention on the individual, treating the targets of intervention as if they were not members of families, peer groups, social networks, communities, or a broader society. Prevention emphasis has been placed on cognitive and motivational variables, including how individuals interpret behavioral information, how they value that information, and how capable they feel about using the information in changing their behavior. The literature on IDUs and AIDS risk was especially noteworthy in this regard.

Although health psychology has made important contributions to social and behavioral AIDS prevention research, it is becoming increasingly recognized that “the usefulness of such approaches . . . is limited . . .” (Aggleton et al. 1994) and that consequently the focus of much AIDS research has been extremely narrow. Concern about the level of impact achieved by individual-focused prevention and renewed appreciation of the importance of social and behavioral research in enhancing the efficacy of prevention designs have produced an effort to identify social-level approaches that are relevant to confronting the epidemic (Singer 1992; Singer and Weeks 1996). This shift has contributed to the newfound appreciation (beyond anthropology and related bases of support) of ethnography. Indeed, prestigious institutions like the National Research Council (Turner et al. 1989) have called for expanded ethnographic research on behavioral risks and social risk contexts (Miller et al. 1990). Thus, it would be appropriate to say that this research volume arrives at the juncture between a history of individual-focused prevention research in AIDS and a future that, to have any significant impact at the local, national, and international levels in bringing the AIDS pandemic under control, must move beyond individual to group, societal, structural, and other supraindividual prevention levels.

Why has it taken this long to begin a serious consideration of alternative, social-level approaches in making this transition? And why have anthropological frames of understanding not been more prominent in AIDS prevention? Various factors have been suggested to account for the limited presence of anthropological models and concepts in existing AIDS prevention research:

- Anthropologists, generally, were late participants in AIDS research and thus entered the field as adjuncts to other health social scientists, who received initial funding and continued to dominate behavioral funding thereafter.
- Anthropologists thus far have focused much of their theoretical energies on challenging the problematic nature, first, of “risk groups” and later of constructed (and not naturally occurring) “behavioral groups” as useful epidemiological categories in AIDS prevention rather than on building alternative social-level theoretical approaches.
- Anthropologists often have had difficulty in operationalizing their concepts into testable hypotheses because they have tended

to be guided by broad macroscopic paradigms rather than smartly labeled midlevel theories.

- The widespread adoption of health psychology theories in AIDS has been driven by a perceived need for rapid results that can lead to publications and justify the budgets of research institutes in the midst of a spreading epidemic.
- The question of anthropology's role in AIDS is being raised at a peculiar moment in the discipline's history, a moment when the body of ideas that unify the field is, to some degree, in disarray. Central to this last item is a problem that has been called a "crisis of representation" (Marcus and Fischer 1986), which involves a much discussed suspicion that anthropology lacks adequate means of either knowing or describing the social reality of other peoples and other places. As Geertz has argued, "what we call our data are really our own constructions of other people's constructions." The resulting "epistemological hypochondria" (Geertz 1988, p. 71) has produced a self-absorbed anthropology, a trend that remained prominent throughout the 1990s.

AIDS research, however, demands confidence. To be useful, models and approaches must be "good enough" to produce useful results in AIDS prevention. As Kotarba (1990, p. 260) observes, "the issue of whether ethnography can arrive at the 'truth' about people's everyday way of life . . . has largely been waived in favor of the practical goal of achieving the particular kinds of truths needed to establish programs to save people's lives." Acknowledging her "weariness" with postmodern critiques, particularly in the context of "perilous times," Scheper-Hughes (1993, p. 28) comments, "I am inclined toward a compromise that calls for the practice of a 'good enough' ethnography."

This is the spirit that has guided the work of the anthropologists who have contributed to this volume. They have been far less concerned with debating grand theory, pondering anthropological claims to authority, or critiquing literary conventions used in ethnographic writing than with "recapturing" ethnography and related anthropological approaches and understandings to meaningfully address life and death issues, contribute to the formulation of public health policies, and positively influence the implementation of social programs.

Ironically, events that led anthropology to the frontiers of relevance in AIDS prevention research have caught many members of the discipline off guard. For too many years, anthropologists had grown accustomed to having little impact on health and social policy or programs. After having been told for decades that their approaches were “soft,” their data impressionistic, and their conclusions too broad to be of value in policy formulation, anthropologists were surprised to discover a growing appreciation of their concepts and methods in AIDS work, particularly in AIDS and drug abuse prevention research. Yet, unavoidably, a number of features of the pandemic drew attention to anthropological approaches, including the following:

- The nature, social contexts, and potential for change of AIDS risk behavior—especially sexual practices and injection drug use—are poorly understood, suggesting the importance of naturalistic studies of behavior of the kind anthropologists commonly do.
- It is difficult to measure socially stigmatized and hidden risk behavior like drug injection and sex-for-drugs exchanges through survey research that relies solely on out-of-context self-report, which suggests the importance of field observation in natural settings.
- It is generally recognized that it is difficult if not impossible to use survey research to grasp the meanings people invest in and derive from their behavior and hence how they will understand and respond to suggested behavioral changes that foster HIV prevention.
- Beyond meanings, social conditions unnoticed by structured survey questions (because no questions about them are included in the research instruments) may make change difficult or impossible despite the expressed interest in change voiced by respondents.
- As noted above, a long history of anthropological research demonstrates that there are always unexpected discoveries in the field, which is a much needed capacity in determining how to further change behavior or change the behavior of those who have not been motivated or able to change in particular contexts.

- There is a broadly recognized need in the AIDS field for socially and culturally relevant interventions, in that nonsensitive “imported” efforts have failed to equally reach and contribute to changes in behavior in so-called special populations.

## **ANTHROPOLOGY AND EPIDEMIOLOGY: AT THE CROSSROADS OF COLLABORATION IN THE FIGHT AGAINST AIDS**

As members of a discipline that takes the social group as its primary level of theoretical concern and understands behavior in a holistic social context as a primary focus, AIDS-involved anthropologists have welcomed the shift in attention that is now being called for in the AIDS field. In trying to bring anthropological skills to an international public health crisis like AIDS, these anthropologists have been concerned with developing approaches for unifying their contextually grounded methods with those of a broad public health field like epidemiology. The rationale for consideration of this accord is specified by Agar:

Epidemiology is . . . the study of human disease, and those humans are busily thinking, feeling and acting on their own terms, terms which may not be understandable to an outsider. To the extent that a “disease” involves subjective worlds—and recent knowledge of interacting neuroanatomical systems shows that all of them do—then ethnography with the capacity to document those worlds can offer up missing epidemiological data. Epidemiology, on the other hand, can add ways to generalize ethnographic results (Agar 1996b, p. 391).

Since the start of the AIDS pandemic, there has been a dramatic expansion in epidemiological research. By the end of 1991, AIDS epidemiologists were conducting cohort studies of the patterning of HIV incidence, prevalence, susceptibility, risk, transmission, spread, morbidity, and mortality in more than 20 countries. In this process, epidemiology is changing, including adopting a social perspective (or, more accurately, readopting its lost 19th-century concern with the social context of disease transmission and control) that makes it much more open to collaboration with anthropology. Although anthropologists have been collaborating with epidemiologists for many years (Janes et al. 1986; Rubenstein 1984; True 1990), they have come to recognize that, in the context of the AIDS pandemic, there is an urgent need to enhance and expand these interdisciplinary

initiatives. Yet this realization is not without problems. There is some discomfort among anthropologists about the role they have played thus far in collaborative efforts. The nature of this concern was voiced by Clatts in an article that has been widely discussed by anthropologists working in the pandemic:

I am . . . growing increasingly skeptical about the directions in which AIDS prevention research is going, especially that being conducted by social and behavioral scientists. Of particular concern is the fact that AIDS prevention has become an exercise in behavioral modification . . . More troubling still is the way in which the language of social control has slowly but surely crept into our (anthropological) discourse, such that it is now commonplace to find anthropologists talking about such things as “denial,” “relapse,” and “non-compliance” . . . I submit, however, that the process has gone terribly awry, that the undaunted search for quick-fix models forces us to crawl into very narrow boxes, that it jeopardizes our ability to see the world as it is, as well as our ability to offer constructive ideas about how to change it (Clatts 1994, p. 94-95).

This comment draws attention to the issue of how anthropologists can work collaboratively with epidemiologists and other behavioral scientists in AIDS prevention research without sacrificing insights and understandings about human behavior that have been gained through more than 100 years of anthropological research. As noted, central to the orientation of anthropology is a deeply ingrained appreciation of the fundamental importance of entering into the cultural and social worlds of the people under study—in this case, drug users, drug distributors, commercial sex workers, gang members, police, service and treatment providers, and other players in the street drug scene—and attempting to understand their constructions of reality, the shape and character of their social relationships, and the ins and outs of the physical settings in which their lives unfold. Furthermore, anthropologists bring a holistic understanding to this endeavor, one that goes beyond the immediate ground of observation to link microlevels and macrolevels of analysis—in this case, one that ultimately links street drug use to the laundering of drug money by major financial institutions, AIDS rates among street IDUs to social discrimination against drug users by multimillion-dollar public health care institutions, and the consumption of licit and illicit substances in ramshackle “abandoned” buildings in the inner city to the consumption of the same substances

(e.g., alcohol, cocaine, heroin, marijuana, amphetamines) in the plushly carpeted homes of middle- and upper-class suburbs. From the anthropological side, fuller collaboration with epidemiologists will be influenced by anthropologists' ability to retain this type of ethnographically grounded holism rather than be expected to automatically embrace the external categories, frames, and values of the public health field.

Toward this end, a conference was held in Washington, DC, in September 1996 with the express purpose of encouraging the development of successful and productive collaborative AIDS prevention research between epidemiologists and anthropologists. The goal of this conference was to significantly advance the integration of anthropological and epidemiological theory and methods for the development of research on drug use and the prevention and control of AIDS. The conference had four broad aims: (1) to demonstrate the relevance of anthropological theory/methods for epidemiological research on drug use and the prevention and control of AIDS, (2) to describe current applications of anthropological theory/methods in epidemiological AIDS and drug research, (3) to identify emerging scientific paradigms in collaborative research, and (4) to articulate a direction for future ethnoepidemiological AIDS prevention research. With encouragement from Dr. Richard H. Needle, chief of the Community Research Branch at NIDA, the conference was organized by the American Anthropological Association's Commission on AIDS Research and Education, and supported by the Wenner-Gren Foundation for Anthropological Research and NIDA. Most of the chapters in the volume were developed originally for this conference and revised for inclusion here. Several other chapters were added to expand the scope of the volume.

The special concern of this volume is AIDS prevention research that addresses risk among drug users, their partners, and their children. Although AIDS was first identified among gay men in 1981, not long after, the disease also began showing up among IDUs and their children. During drug injection, blood—the primary medium of HIV—enters the user's needle and can be passed directly to subsequent users of the needle or indirectly via other injection paraphernalia (e.g., "cookers" [small containers used to mix drugs], cotton filters, rinse water). Since 1987 the annual percentage of new AIDS cases associated with injection drug use in the United States has increased from 17 to 36 percent (including IDUs, heterosexual sex partners of

IDUs, and children of IDUs or sex partners of IDUs), and in parts of the United States, like the Northeast, IDUs constitute the majority of AIDS cases. Nationally, approximately 200,000 individuals have been diagnosed with AIDS who are IDUs, heterosexual partners of IDUs, or children whose mothers were IDUs or sex partners of IDUs. Of AIDS cases reported among women in the United States, 66 percent are IDU-associated. Cases of IDU-associated AIDS are disproportionately high among heterosexual ethnic minorities, especially blacks and Hispanics. Although AIDS prevalence levels have begun to drop among IDUs in the highest prevalence areas in the United States, they continue to rise among other drug abusers, including crack cocaine users (CCUs). Crack cocaine-related sexual risk now is a primary factor in sexually transmitted AIDS cases.

In other parts of the world, AIDS cases among IDUs continue to grow. It is estimated that there are as many as 5.5 million IDUs in the world. Although the largest number of IDUs is in the United States, substantial numbers are reported in Western Europe (especially the United Kingdom, France, Spain, and Italy), Asia (especially China, Thailand, Myanmar, Hong Kong, India, and Malaysia), Latin America (especially Argentina, Brazil, and Puerto Rico), and in Nigeria, Canada, and Australia. Moreover, there is evidence that the number of IDUs in the world is growing and that the practice of drug injection is spreading to new areas where it previous was not known (Fontanet and Piot 1994; Mann et al. 1992).

Consequently, understanding AIDS risk and prevention among IDUs, CCUs, and other drug users remains a significant issue in public health research. Over the years, many anthropologists have contributed to understanding the nature of illicit drug use and its relationship to a wide range of poor health outcomes (Agar 1973; Hamid 1990; Waterston 1993). Anthropological research also has contributed to the development and implementation of effective intervention strategies among drug users both nationally and internationally (Bolton and Singer 1992; Lindenbaum 1992; Singer 1997b). Particularly important has been the role that anthropologists have played in reaching "hidden populations," such as out-of-treatment IDUs, CCUs, individuals involved in sex for drugs or money exchanges and survival sex (e.g., sex for shelter) exchanges, dually at-risk individuals (e.g., drug-using men who have sex with men), and drug-involved and other high-risk youth (Bennett and Cook 1990). The chapters in this volume bring together insights from this research and seek avenues for fuller collaboration with the

social epidemiology of AIDS. It is impossible to include in this limited volume the wide range of work representative of anthropologists engaged in HIV prevention and AIDS research. However, the contributors discuss many of the critical topical, methodological, theoretical, and ethical contributions that make up the anthropology of drug use and AIDS as an emergent domain.

## OUTLINE OF THE VOLUME

This research volume begins with an examination by Singer, Marshall, and Clatts of anthropological and epidemiological theoretical and methodological foundations in prevention research on drug abuse and HIV/AIDS risk. Results of studies combining ethnographic and epidemiological approaches follow, along with a discussion of ethical concerns related to ethnographic studies on drug use and HIV prevention. Finally, a historical overview of ethnographic research on street drug use prior to the emergence of AIDS is presented.

In Chapter 2, Singer develops a critical biocultural model of drug use and health risk. He argues that anthropology brings four notable strengths to the public health study of health and health-related behavior of drug users: (1) The discipline combines an encompassing perspective on human populations with a visceral commitment to the collection of fine-grained, highly contextualized data; (2) anthropology asserts that human beings' biological and sociobehavioral sides must be studied in tandem as mutually influencing phenomena; (3) anthropology recognizes the critical importance of studying human behavior in relationship to the configuration of local meanings and emotions invested by people in acts, objects, relationships, and locations; and (4) although anthropology tends to narrow its focus to the intensive study of micropopulations, communities, and groups, it recognizes that issues like power, exchange, labor, mobility, and disease crosscut social boundaries.

In Chapter 3, Page and Trotter address the implications of anthropology's often atheoretical stance in multidisciplinary research on drug use and AIDS. One advantage, they note, is that this approach facilitates collaboration with other disciplines. However, disadvantages include difficulties in positing clear hypotheses that can be tested through focused research. Midlevel theories, such as network theory, acculturation theory, and health systems theory, they argue, offer direction for ethnoepidemiological research. This chapter summarizes

several models for the successful use of anthropological midlevel theories. The authors demonstrate that anthropological theory and methods contributed significantly to the design and refinement of outreach strategies to contact and recruit project participants, the creation of sample designs for both establishing and monitoring the epidemiological conditions and trends in HIV and drug use risks on local and national levels, and the generation of culturally competent interventions.

In Chapter 4, Clatts, Heimer, Sotheran, and Goldsamt examine the social ecology of high-risk drug injection practices, an understudied topic in AIDS prevention research. Much of the current research on drug injection practices emphasizes the individual-level characteristics of the IDU. To overcome this gap in understanding, the authors focus on the interdependent processes of drug acquisition, preparation, and injection and their possible consequences for HIV transmission. They describe the nature and prevalence of a range of these injection-related practices in terms of potential HIV transmission. They also demonstrate the power of integrating ethnographic data and laboratory studies of viral activity and call attention to the importance of locating HIV risk behavior in particular social contexts.

In Chapter 5, Sterk explores gender-specific aspects of HIV risk-taking among women who use drugs. She describes several methodological issues that arise in efforts to combine anthropological and epidemiological strategies in studying gender issues like reciprocity and power in AIDS transmission. Data for this chapter come from her ongoing ethnographic research of female drug users and their HIV risk.

Manderson, in Chapter 6, assesses anthropological approaches in prevention research on sexual behavior, drug use, and risk for HIV/AIDS in Asia and Australia. She presents two separate but related points: (1) the merit of multidisciplinary research to ensure valid and useful results for the development of public health interventions and (2) the importance of research collaboration with communities to identify risk behaviors and to develop, deliver, and monitor interventions that are acceptable to and sustainable in particular groups. Manderson's presentation draws on research conducted by researchers of the Australian Centre for International and Tropical Health and Nutrition in Australia (with Indigenous Australians) and in Southeast Asia (particularly Thailand but

also Indonesia). This research involves close collaboration across public health disciplines and among institutions and reflects an interdisciplinary approach to public health research.

In Chapter 7, Curtis and Hamid examine the relationship between drug-dealing street gangs and violence in New York. Specifically, they assess the “Third Crown,” or the officer in charge of arbitrating disputes and authorizing the use of force, in the Brooklyn chapter of the Latin Kings gang. Using a review of actual cases arbitrated by the Third Crown in 1996, they report that far from promoting violence, the Third Crown worked to contain it. Contrary to much of the existing literature on gangs and violence, Curtis and Hamid argue that the formation of the Latin Kings and Queens and other recent gangs was an indigenous response to violence fomented by deteriorating neighborhood conditions, the exigencies of drug markets, and the police activity used to curb the drug trade.

In Chapter 8, Ware and Tugenberg examine the challenges associated with access and adherence to combination antiretroviral therapy for HIV/AIDS among IDUs. They report the preliminary results of an ethnographic study of the social course of adherence to antiretroviral therapy. Specifically, Ware and Tugenberg present a detailed case focusing on the development of “readiness” for antiretroviral therapy. They demonstrate that readiness—for medical treatment, drug treatment, and physical or psychiatric rehabilitation—is a social process, developing continuously and extending up to and beyond the initiation of treatment.

Chapter 9 explores ethical issues in ethnographic federally funded research on drug use and HIV/AIDS. Singer, Marshall, Trotter, Schensul, Weeks, Simmons, and Radda describe the ethical principles underlying research and Federal standards for the ethical conduct of research. They call attention to the unique moral dilemmas encountered by anthropologists working in the area of drug use and HIV prevention. A range of specific ethical problems are examined, such as sharing drugs with study participants; procuring, holding, or transporting drugs for participants; and having sex with study participants. This chapter builds on discussions at the 1998 Workshop on Ethical Issues in Illicit Drug User Research convened by the AIDS Advisory Committee of the Society for Applied Anthropology.

In Chapter 10, Marshall outlines a model for resolving ethical conflicts in ethnographic research on drug use and HIV prevention. She

argues that instead of using the model as an “algorithm” for moral decision making, this approach should be viewed as a process for examining the full range of social values and beliefs that may be relevant to particular ethical dilemmas that emerge.

In the final chapter, Singer describes the history of ethnographic research on street drug use before the AIDS pandemic. His examination of earlier ethnographic work demonstrates the continuity between prior anthropological studies on substance abuse and current research on drug use in the context of HIV/AIDS. His analysis and critique show the powerful ways in which the ethnographic tradition has contributed to the development of a significant and ongoing anthropological commitment to ethnographic explorations of drug use and HIV prevention.

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# **Chapter 2. Toward a Critical Biocultural Model of Drug Use and Health Risk**

*Merrill Singer*

## **ABSTRACT**

Anthropology brings four notable strengths to the study of health and health-related behavior of drug abusers. First, the discipline combines an encompassing perspective on human populations—an abiding concern with interconnections that we commonly term “holism”—on the one hand with a visceral commitment to the collection of fine-grained, highly contextualized data—a methodology we call ethnography—on the other. In other words, while our frame of understanding assumes complex interconnections, our primary research method dictates the indepth study of specific, on-the-ground behaviors and beliefs in their natural contexts. In substance abuse research, this has allowed anthropology to play an important role in discovering concrete patterns of risk and the social patterns and processes that promote and support risk behaviors.

Second, anthropology asserts that our biological and sociobehavioral sides must be studied in tandem as mutually influencing phenomena. This model focuses attention on human health in its interrelated bioenvironmental and sociocultural contexts. That is, bioculturalism recognizes “that every major change in society, population, use of land, climate . . . nutrition, or migration is also a public health event with its own pattern of disease” (Lewontin and Levins 1996, p. 104). Anthropology’s holistic and biological orientations promote an approach to the health of drug users that considers not only the full range of relevant conditions—from STDs to TB, and from the hepatitis B virus to HIV—but also nutrition, living conditions, and stress factors—as intertwined, mutually reinforcing factors that shape health status.

Third, anthropology recognizes the critical importance of studying human behavior in relationship to the configuration of local meanings and emotions invested by people in acts, objects, relationships, and locations. This recognition has immediate implications for the study of health among drug abusers, because many of the behaviors deemed risky from a public health perspective are integral parts of complex webs of social meaning and culturally

generated patterns of emotion and feeling. Fourth, although anthropology often tends to narrow its focus to the intensive study of minipopulations, communities, and groups, it recognizes that issues like power, exchange, labor, mobility, and disease crosscut social boundaries. Focusing too narrowly at the microlevel—for example, behavior within a shooting gallery—may distort the causes and consequences of behavior. The corrective involves situating concrete observable acts within determinant macrolevel analyses. From this vantage point, drug abuse research cannot remain isolated as the restricted study of the minds, bodies, and behavior of an allegedly bounded netherworld of stereotypical social deviants, but must encompass the broader social web of bank laundering of drug money, landlords and employers who contribute to the ghettoization of misery, policymakers who reinforce structures of inequality, health care providers who see drug abusers as unworthy patients, stores and restaurants that purchase (at discount prices) the items drug users steal to support their “habits,” pharmaceutical companies that produce (with at least some level of awareness) many drugs that quickly find their way into the illegal trade in drugs, airline and shipping firms that transport drugs, police who are on the payroll of drug sellers, a growing number of for-profit prison builders and managers who warehouse petty drug dealers (most of whom are addicts themselves), stores that knowingly (if unadmittedly) sell drug paraphernalia (like crack pipes), diabetics who sell their used or surplus needles to street IDUs, suburban drug users who come to the inner city to buy drugs—among many others who contribute to the maintenance of street drug culture. This chapter explores these four attributes of anthropology as part of an effort to construct a critical biocultural approach for the study of health among inner-city drug users.

**Key words:** Injection drug use, HIV/AIDS, critical bioculturism, anthropology

## **INTRODUCTION**

For those whose personal and professional lives over the past two decades have been lived close to the epidemic, it is becoming difficult to remember the time before acquired immunodeficiency syndrome (AIDS). This is true especially for people living in developed countries. Today, infectious diseases—not just human immunodeficiency virus (HIV)/AIDS but also a host of other

recently identified afflictions such as ebola, necrotic hepatitis, and various hemorrhagic fevers—have become regular fare, from nightly network news programs to polite dinner conversations. This was not the case just a few years ago. The notable successes of vaccines and antibiotics created a climate in which it was increasingly possible to believe that infectious diseases were being swept into the dustbin of history. Not so many years ago, the successful worldwide campaign to eliminate smallpox was being heralded as a historic epidemiologic demarcation dividing the ancient and modern worlds. Consequently, in 1968 the U.S. Surgeon General William Stewart told Congress that the time had come to “close the books on infectious disease” (quoted in Garrett 1992, p. 825) and shift health resources to the chronic conditions of a sedentary and aging population. Congress complied. Budget cuts during the early 1970s eliminated most of the tropical and infectious disease units run by both the U.S. Public Health Service and the U.S. military. Federal funding for medical entomology, parasitology, and host pathology at most universities dried up. By the early 1980s, infectious diseases claimed less than 5 percent of total U.S. disease expenditure dollars. The mood of this period is captured in the fourth edition of *Natural History of Infectious Disease*, the classic volume on the evolution of disease, published in 1972 before the advent of AIDS, in which Burnet and White (1972, p. 3) observe; “Young people today have had almost no experience of serious infectious disease. The classical pestilences, smallpox, plague, typhus and cholera have been banished effectively for a hundred years or more and in the last half century the standard childhood infections have progressively lost their power to kill.”

The coming of AIDS destroyed this now dated, optimistically naive perspective. Infections, new and old, it was painfully realized, retained their “power to kill,” and on a global scale. As Fee and Krieger note,

AIDS shocked the western medical world, appearing as a throwback to an earlier era of infectious and fatal epidemics. AIDS seemed to appear out of historical context, at once entirely new, but also old; it properly belonged to a distant and less comfortable past, before economic and scientific progress had combined to banish the ancient plagues (Fee and Krieger 1993, p. 324).

In addition to taking thousands of lives and causing untold human suffering, especially in populations already subject to poverty and

social opprobrium, in quick order AIDS undermined a socially constructed reality of health and illness shared by medical professionals, health researchers, disease control specialists, and the general public.

In accounting for the ill-preparedness of the medical and public health systems to deal with the AIDS pandemic, Lewontin and Levins (1996, p. 106) point to *specific shortcomings of epidemiological understanding*, noting “The development of a coherent epidemiology is thwarted by the false dichotomies that permeate . . . thinking . . . the either/ors of biological/social, physical/psychological, chance/determinism, heredity/environment, infectious/chronic and others . . .”

By way of illustration, they cite cholera, a disease that historically has taken a nightmarish toll on human life and well-being and continues to do so. Focusing attention on the “agent” of cholera and neglecting the “host” and the “environment,” a concern also noted recently by Agar (1996), epidemiologists have viewed cholera outbreaks as

the coming of cholera bacteria to lots of people. But cholera lives among the plankton along the coasts when it isn’t in people. The plankton blooms when the seas get warm and when run-off from sewage and from agricultural fertilizers feed the algae. World trade is carried in freighters that use sea water as ballast which they discharge before coming into port, along with the beasts that live in that ballast water. The small crustaceans eat the algae, the fish eat the crustaceans and the cholera bacterium meets the eaters of fish. Finally, if the public health system of a nation has already been gutted by structural adjustment of the economy [adjustments often brought on in recent years by the dictates of lender institutions like the World Bank], then the full explanation of the epidemic is, jointly *Vibrio cholerae* [the bacterial agent] and the World Bank [a key determinant of the social environment] (Lewontin and Levins 1996, p. 106).

As this bold conclusion implies, embrace of a false dichotomy—in this case between the biological and the social—leads to narrow and distorted understanding. Instead, Lewontin and Levins (1996) urge the development of a unified or holistic perspective for epidemiology that is sensitive to synergistic interaction among bioenvironmental,

sociocultural, and politicoeconomic factors. In other words, they call for the creation of a *critical biocultural model of epidemics*.

Unfortunately, in responding to the pressing realities of AIDS, the public health field has not heeded Lewontin and Levins and shed its Cartesian dualistic approach (Singer 1996a). Rather, the false dichotomy between epidemic and chronic diseases has been redeployed yet again. Noting that the history of AIDS has passed through two main phases, Fee and Krieger (1993, p. 324) observe: “In the first [phase], AIDS was conceived of as an epidemic disease . . . by analogy to the sudden devastating epidemics of the past; in the second [phase], it was normalized as a chronic disease, similar in many ways to diseases such as cancer . . .”

Characteristically, in the second phase, health policy professionals reasserted their dominance. AIDS vaccine research, new treatment options, cost of care, and state-of-the-art clinical management increasingly became the focus of attention in the AIDS field, with resultant questions being raised about policymaker commitment to prevention. The emergence of a new generation of AIDS treatments, which was discussed with great optimism at the 1996 International Conference on AIDS, has produced an ironic twinge of pessimism among those who focus on prevention (Merson 1996). Even more significantly, the chronic disease model is problematic because of its tendency to be “thoroughly individualistic and rarely challenge the conditions of the production of disease” (Fee and Krieger 1993, p. 332). Moreso than the infectious disease model, the chronic disease approach narrows examination of etiologic agents, while focusing attention on the disease course within specific organs and organ systems.

Fee and Krieger (1993) have proposed an alternative paradigm that views AIDS as a “collective chronic infectious disease.” Such an approach eliminates the false dichotomies exposed by AIDS between the individual and the social, on the one hand, and chronicity and infectivity on the other. *Urging movement toward a similar shift in public health thinking about AIDS and related health issues among drug users is the first goal of this chapter.* However, beyond Fee and Krieger, the chapter urges overcoming the biological and social dichotomy as well. As suggested by Lewontin and Levins (1996), biological processes unfold in a world shaped and reshaped by social forces, just as society, in all of its complexity, must respond to pressing biological forces, including epidemics. *Mobilizing these insights for the*

*formulation of a critical biocultural model is the second goal of this chapter.* Finally, as Agar (1996) argues, contemporary health problems have generated a pressing need to link ethnography and epidemiology, a transition that, in part, will entail a return to an older, 19th-century Virchowian approach to public health research, which carried with it a concern with social, cultural, and political aspects of the human situation as well as the biological nature of disease. *The final goal of this chapter—the one that will be used to structure the presentation—is to suggest the significant role anthropology can play in the development of the kind of critical biocultural model that is capable of surmounting the public health dichotomies mentioned above and serving thereby as a paradigm for a renewed ethnoepidemiology of substance abuse and health risk.*

## ATTRIBUTES OF ANTHROPOLOGY

Anthropology brings four notable strengths to the study of the health and health-related behavior of drug users. These strengths have immediate relevance for the development of a critical biocultural model. Each of these is examined in turn.

### Holism

First, anthropology combines an encompassing perspective on human populations—an abiding concern with underlying interconnections that anthropologists commonly term “holism”—with a visceral commitment to the collection of fine-grained, highly contextualized, experience-near data, an approach Scheper-Hughes (1993, p. 4) has described as “an anthropology-with-one’s feet-on-the-ground.” In other words, while the anthropological frame of understanding assumes complex interconnections underlying social behavior, the field’s primary research method—ethnography—dictates the indepth study of specific “on-the-ground” behaviors and beliefs in their natural contexts in identified populations. In substance abuse research, this has allowed anthropology to play an important role in discovering concrete patterns of risk and the social relationships and processes that promote and support risk behaviors. For example, as part of open-ended interviews with injection drug users (IDUs) in shooting galleries and other injection sites in Hartford, CT, members of the author’s collaborative research team at the Hispanic Health Council and at the Institute for Community Research have heard occasional references made to a folk illness that IDUs refer to as

“cotton fever.” During an interview with a female IDU, for instance, the following exchange<sup>1</sup> occurred:

Q: Do you share cottons?

A: No. I like new cottons because I hate cotton fever.

Q: Is it because the cotton goes into the needle and into your arm?

A: Some sort of dirt or something gets inside; that's the way I was told. You can get it sometimes off the dope if there's a speck of dirt in your dope. Or somebody's hands are dirty. Or old cotton, reused cotton, will give you cotton fever. What it is, you break into a deep sweat and stuff and you get the chills where you can't control your body and stuff. It's bad; it's rough. Your teeth be chattering; you got no control over your body. That's 10 times worse than being dope sick. Horrible feeling. Horrible. Only one thing will stop it is another bag of dope; knocks it right out.

A male IDU added the following information:

Q: Have you heard of cotton fever?

A: I've had cotton fever a lot. Actually, I got that mostly from using Q-tips. There's fiberglass in them. Cotton fever is no joke. For me to get rid of cotton fever, I had to get another bag [of heroin] in my system. I had the chills, fever. I was high, but it was like I was dope sick, triple time. I couldn't get out of bed; I couldn't walk until I got a bag of dope. The crazy part was that I was high, but I was sick. I had cotton fever a lot. I try not to get it; it is not fun. Now I only use real cotton. I think it is the fiberglass that did it to me.

It is evident that while IDUs have somewhat varying understandings of the cause of cotton fever, they are in agreement that it is a particularly painful illness, one to be avoided if at all possible. Both of the informants quoted above, for example, make a special point of stressing that having cotton fever is several times worse than being “dope sick” (i.e., experiencing initial heroin withdrawal symptoms). Judging from the symptoms and the self-administered folk cure (i.e., injecting more heroin), it may be that the symptoms of cotton fever

are caused by using highly diluted drugs at the point that an individual is already in the early stages of withdrawal. Whatever the underlying cause, however, folk ideas about cotton fever appear to operate to some degree as a subcultural barrier to cotton sharing, a known risk behavior for HIV transmission (Koester and Hoffer 1994). Discovery of this type of folk barrier to risk, a behavior that could be incorporated more overtly into risk-reduction education (e.g., with prevention messages that urge “avoid cotton fever; do not share or reuse cottons”), is exemplary of the type of contribution to public health that can emerge from ethnographic research.

Another example of the discovery role of ethnography can be seen in recent examinations of the impact of violence on drug use and AIDS risk. In our interviews with inner-city drug users in Hartford, the theme of violence is a common one (Singer 1996b). The connection of violence to both drug use and AIDS risk can be seen in the following three case examples.

**Case 1.** Migdalia, a 35-year-old Puerto Rican woman with an eight-bag-per-day heroin and cocaine drug habit, reported,

I started smoking; that's how my addiction started, and I did it 'cause I had a lot of problems with my dad. He . . . hit me all the time, without any reason. Every time he went by my side, he would slap me. He did this since I was 12 until I was 16, and he made me so nervous all the time. My nerves were totally destroyed, and that problem made me start the cigarette vice and then, right after that, I started to use “pasto” (marijuana). That's when I was 16. I had to leave my house because he ran after me with a machete. He got upset sometimes 'cause I was talking to a guy. God forgive me, but I think that even though he was my father he was interested in me . . . He locked me in the house all the time and I told him, “I'm not gonna be yours.” That's when he really got crazy and he said he was gonna kill me with the machete. So that's how I started smoking cigarettes, 'cause I needed to calm my nerves . . . And then I started smoking pasto, and with that it was easier because I could relax more and forget about my problems. And a little after that I smoked “perico” (cocaine). You know, sometimes you think that by doing this you can forget your problems; you think “maybe I will smoke and distract myself and forget all that.”

**Case II.** In the case of Alicia, a 28-old-women with a 16- to 18-bag-per-day habit, drugs appear to offer a more permanent form of relief. She reported, "The drugs make me forget. Y'know, sometimes I shoot up to see if I can die; y'know leave this world, 'cause I'm tired and I feel lonely and I don't have nobody." The source of Alicia's misery was abuse from her husband. She noted,

I was with the father of my kids. I didn't use drugs. The only thing that I used to smoke was cigarettes. Since I wasn't doing anything, I used to be at home, taking care of the kids, cooking. I always had a clean house, and he would come home to beat me so bad. Then I used to think: "I am a housewife. I didn't do anything wrong. Why is he hitting me? Why does he do this?" He just loved to beat me up. He knocked one of my teeth out. He would send me to the hospital. So that's how I started using drugs, with my cousin, but that's why I started . . . My life is not easy. I wish I could have at least 1 day of peace, but I can't. Imagine what it is like to be watching TV or something and all of a sudden someone is punching you in the face or slapping you and you don't know why.

**Case III.** Ed is a 35-year-old man whose mother is Puerto Rican and father, now deceased, was Italian. He began using drugs at age 10 with his friends as they patrolled the streets looking for opportunities to steal and get into fights. At age 14, Ed began selling heroin on the street for his father, who was a local dealer. Ed reported that his father beat him up nearly every day, using the slightest pretext as reason for punishment. Just before he turned 15, Ed shot and killed a man who had tried to steal the drugs he was selling. Ed stated that his father was proud of him for "being a man" and defending the drugs and killing the thief. Nonetheless, Ed was tried as an adult, convicted, and served 5 years in prison. On his release, Ed went back to using and selling heroin. At the time he was interviewed for the project, he had been using drugs almost 25 years, had been in jail several times for drug dealing, was a gang member, and was injecting three bags of heroin a day. Soon after Ed's first interview, he was stabbed in the chest by several men sent by a local drug dealer. Ed had stolen drugs from this man, a local gang leader, and the stabbing was in retribution. In the weeks after the stabbing, Ed became increasingly demoralized. He felt "weak and old" because he had been caught without a weapon and had allowed his attackers to get the jump on him. "In the old days," he reported, "that would have never happened. I'd have fought back, not just to defend myself like

I did, but to have killed one of them." During this period, Ed's drug use increased significantly, and he began drinking heavily as well. He attributed the change in his substance abuse patterns to feeling depressed about the stabbing.

These three ethnographic examples suggest that one important behavioral connection among violence, drugs, and AIDS is the risky use of drugs as a form of self-medication to buffer the painful emotions/consequences of being a victim of violence. This connection is affirmed by the recent review by Downs and Harrison (1998) of existing retrospective and prospective studies on the relationship between childhood maltreatment and substance abuse later in life. They conclude that the experience of child abuse "appears to lead to increased feelings of depression and anxiety which, while not sufficient to result in the diagnosis of a mental health disorder, place the victims at greater risk of developing substance problems, possibly as a result of self-medication" (Downs and Harrison 1998, p. 44).

Drug treatment and AIDS prevention efforts that fail to address the role violence plays in driving the behaviors targeted for change may fail to achieve their intended objectives, because they ignore a critical component of the client's life experience and a determining feature of the client's behavior.

### **Biology and Social Behavior: Mutual Influences**

Second, anthropology, especially as it is practiced in the United States, asserts that our biological and sociobehavioral sides must be studied in tandem as mutually influencing phenomena. As Levins and Lewontin (1998, p. xv) stress, "Anthropology, properly construed, is not separable into the physical and the social." Although this understanding often has been honored more in platitudinous self-description than in actual day-to-day practice, within the domain of medical anthropology, a resolutely biocultural approach has been central. This model focuses attention on human health in its interrelated bioenvironmental and sociocultural contexts. In other words, bioculturalism recognizes "that every major change in society, population, use of land, climate . . . nutrition, or migration is also a public health event with its own pattern of disease" (Lewontin and Levins 1996, p. 104). This insight is borne out as false hopes about the "end of infectious disease" have given way to a new appreciation of the biology we cannot escape and of the role of social

factors in the rapidly traveled road from localized epidemics to global pandemics.

Anthropology's holistic and biological orientations promote an approach to the health of drug users that considers the full range of relevant conditions, from sexually transmitted diseases (STDs) to tuberculosis (TB) and from hepatitis to HIV, but also nutrition, living conditions, and stress factors as intertwined, mutually reinforcing determinants of health status. Whereas drug abuse and HIV comorbidity has been a topic of considerable research interest (Needle et al. 1998), the wider scope of interactions between social behavior and various health conditions among drug users—a phenomenon here termed "pathosynergism" from the Greek words for "suffering" and "working together"—is only now being recognized as an important frontier of research. For example, the author's research team in Hartford recently completed a pilot survey and ethnographic study of the nutritional status of female Puerto Rican drug users compared with Puerto Rican women who did not use drugs. Findings indicate important nutritional deficits among the women who reported regular drug use (Himmelgreen et al. 1998). Significantly, research by Beck and colleagues (1996) at the University of North Carolina has shown that malnutrition may contribute to the appearance of more virulent viral strains. In other words, a pathosynergistic interaction between drug use and poor nutrition (caused by drug-induced loss of appetite and nausea and an addiction-driven avoidance of diverting resources from the acquisition of more drugs) may contribute to the evolution of deadlier strains of HIV among drug users.

Work of this sort supports viewing AIDS among street drug users as a *syndemic condition* (i.e., a set of closely intertwined and mutually enhancing health problems that significantly affect the overall health status of a population within the context of a perpetuating configuration of noxious social conditions) (Baer et al. 1997; Singer 1994; Singer and Baer 1995). The AIDS syndemic among drug users is produced by the pathosynergistic effects of *biological factors* (e.g., the retroviral properties of HIV that contribute to rapid mutation, nutritional factors that produce particular mutagenic patterns in the virus, natural selection factors that favor the success of particular viral strains under particular conditions, and the presence of other infectious diseases like TB and STDs that serve as cofactors in HIV transmission and infectivity) and *social factors* (e.g., the impact of class, ethnic, and gender relations on diet, living conditions, health

care, and stress levels). For example, significant stress—an inescapable consequence of the poverty, family rejection and general social opprobrium, poor diet, constant threat of arrest, unstable residence, frequent exposure to street violence and intimidation, and fear of withdrawal and overdose that characterize the lives of many street drug users—has been found to be associated with both increased likelihood and greater severity of early HIV disease progression (Evans et al. 1997). In other words, the evolution of infectious diseases like AIDS must be studied as multifaceted biocultural processes and addressed accordingly by the public health system. As an evolutionary virologist stresses, “Because evolutionary changes in disease organisms depend on past, present, and future cultural environments” (Ewald 1996, p. 9), anthropologists and other social scientists have vital roles to play in the kind of critical biocultural research that is needed to inform prevention efforts.

Important work by Ewald (1996) suggests that behavioral change associated with effective AIDS prevention may contribute to the success of less virulent HIV strains, because slowing the rate at which a virus spreads in a population may favor the survival of the host organism. In a rapidly spreading epidemic, death of the host may actually aid interhost transmission (e.g., people in late-stage HIV disease tend to be highly infectious because their immune-damaged bodies are running rampant with viroids). Moreover, Ewald notes:

Transmission of pathogens through hypodermic needles . . . should favor virulent genotypes. Unlike a potential sexual partner, needles do not shy away from contact with AIDS cases, nor do needles get ill or protect themselves against infection. Moreover, an intravenous drug addict, severely ill with AIDS, probably is more motivated to obtain a fix than sex (Ewald 1996, p. 147).

When routes of viral transmission are limited or encumbered in some way (e.g., when populations are divided into small, dispersed groups such as traditional hunting and gathering societies), death of the host significantly undercuts the number of opportunities for interhost transmission (unless, as in the case of kuru, posthumous transmission is possible). In other words, effective prevention—including programs like syringe exchange that remove infected syringes from circulation—can serve as a force in the natural selection of less lethal forms of disease, revealing a largely unheralded role of prevention in the fight against AIDS.

## **Human Behavior in a Local Context**

Third, anthropology recognizes the critical importance of studying human behavior in relationship to the configuration of local meanings and emotions invested by people in acts, objects, relationships, and locations. This recognition has immediate implications for the study of health among drug abusers because many of the behaviors deemed risky from a public health perspective are integral parts of complex webs of social meaning and culturally constituted feelings. As the study of syringe sharing by IDUs has shown, although this cultural enmeshment of behavior can be overplayed or misinterpreted (Carlson 1996), the centrality of meaning and emotion in human behavior has been demonstrated by a long series of failed public health initiatives that did not consider why people do what they do from the standpoint of their own insider perspective. Drug treatment is a case in point. There has been much criticism of drug treatment for its failure to consider the cultural and social backgrounds of various subgroups of drug users. Numerous studies, for example, have found that women historically have been poorly served by most drug treatment programs, which fail to respond to women's unique needs, sensitivities, understandings, and experiences (Ettorre 1992; Singer and Snipes 1992). The cultural inappropriateness of drug treatment modalities for various minority ethnic populations also has been stressed (Amuleru-Marshall 1995; Ja and Aoki 1993; Singer 1992). Social inappropriateness is also a failing of most drug treatment programs. Borrowing the medical model of individualized disease, drug programs usually are organized to treat individual patients, even though ethnographic findings emphasize that drug users often are immersed in drug-using dyads, families, and social networks (Schiller et al. 1994). As a result, treatment avoidance in such situations may be less an expression of lack of commitment to drug use than it is an emotional commitment to significant social others who will be left behind if one member of the social relationship enters drug treatment. Similarly, key components of reigning drug treatment ideology—such as the 12-step assertion that “once a drug user, always a drug user”—have been found in ethnographic research to clash with the experiences, ideas, and behaviors of many drug users (Jorguez 1983; Teichman et al. 1992; Waldorf 1983). Biernacki (1986), for example, found significant differences among longer term heroin users in terms of their cultural attachments to the drug user lifestyle, social relationships, and identity. Individuals who were not deeply immersed in the drug subculture and who had attachments to conventional social identities and roles were able to cease using

heroin without either treatment or 12-step reinforcement. Similar patterns of unassisted cessation after protracted cocaine involvement also have been reported (Shaffer and Jones 1989; Waldorf et al. 1992).

The issue of syringe sharing among IDUs is another particularly telling example of the importance of social meaning in drug-related behavior, but for an opposite reason than that initially realized. Early in the study of AIDS risk among IDUs, the assertion was made that syringe sharing served as a “symbol of social bonding among people who otherwise have limited occasion to trust one another” (Conviser and Rutledge 1988, p. 45). IDUs were seen as treating syringe sharing as a symbolic act of group intensification (much like breaking bread together in a religious community) that helped forge and maintain otherwise unobtainable supportive social ties. This act has been depicted as being of special importance to IDUs because they are believed to inhabit a dangerous and atomistic netherworld largely devoid of trust or true caring. Ethnographic study of IDUs, however, revealed considerable early aversion to syringe sharing, given folk hygienic beliefs, awareness of hepatitis transmission, and recognition of the potential pain associated with injecting the incompatible blood of fellow IDUs, as well as intensified aversion to sharing that developed with the spread of HIV knowledge (Carlson et al. 1994). Although IDUs generally do not like to share syringes (except, perhaps, with sex partners, relatives, or close friends with whom they also maintain a close, multistranded personal relationship), lack of access to new syringes forces them to buy, rent, or borrow used (and potentially infected) needles. Participation in this behavior persists despite an awareness of HIV risk because of a lack of alternatives for many drug-addicted individuals, a condition produced by the societal creation and enforcement of syringe prescription and drug paraphernalia laws and the resistance of many pharmacies to selling syringes to suspected IDUs (Koester 1994; Singer et al. 1998).

In this light, the appeal of the ritual view of needle sharing appears to lie in dominant cultural beliefs about persons addicted to drugs rather than in the meanings held by drug users themselves. Thus, Bineau (1989) asserts that regular intravenous drug use “quickly leads to a lifestyle often associated with social marginality, a lifestyle where risk taking and danger play central roles.” In the same tone of social distancing, drug users have been described as perceiving “themselves as culturally and socially detached from the lifestyle and everyday preoccupations of members of the conventional world” (Rettig 1999, p. 244). Ethnographic research, however, has questioned the social

deviance model of drug users (Bourgois 1996; Inglehart 1985; Singer 1991; Waterston 1993) while supporting the importance of closely studying the cultural meanings that motivate and mediate social behavior (Good 1994). In researchers' observations and interviews with out-of-treatment, inner-city drug users over the past 10 years, they have seen the painful toll taken by the drug-related syndemic. It is not clear—as researchers talk with drug users on street corners or observe them injecting drugs in dangerous and often abysmally filthy settings in which risk reduction is all but impossible—whether they are witnessing deviance, except that imposed ideologically by isolating impoverished drug users from their immediate and wider social contexts.

### **Microlevel and Macrolevel Analyses**

The fourth attribute of anthropology is its concern with connecting microscopic and macroscopic levels of analysis (DeWalt and Pelto 1985). Although historically much of the work done in anthropology tended to have a narrow focus on the intensive study of minipopulations, communities, and groups, since the 1970s the field increasingly has recognized that issues like power, exchange, labor, mobility, and disease crosscut social boundaries and require macroanalysis as well (Goodman and Leatherman 1998; Mintz 1995; Wolf 1992). Influenced by the field of political economy and its attention to issues of social class and conflicted social interest, macroanalysis in anthropology has adopted a critical orientation. This critical trend has been particularly prominent in medical anthropology and has informed much of the work done by anthropologists in street drug research since the emergence of AIDS (Bourgois 1996; Carlson 1996; Clatts 1993; Farmer et al. 1997; Herdt and Lindenbaum 1992; Koester 1994; Singer 1997; Waterston 1993).

From a critical perspective, it is understood that focus at the microlevel—risk behavior within a drug shooting gallery, for example—distorts the causes and consequences of human decision making and action *unless* situated within determinant macrolevels. From this vantage point, interethnic, cross-gender, and cross-site patterns of risky drug use practices cannot be explained in terms of the personalities, motivations, or even subcultures (in the sense of group values and traditions) of drug users. Although all of these may be important, they do not exist in isolation from the far broader social web of those involved in bank laundering of drug money, landlords and employers who contribute to the ghettoization of

misery, policymakers who reinforce structures of inequality, health care providers who find drug abusers unworthy patients, stores and restaurants that purchase (at discount prices) the items drug users steal to support their “habits,” pharmaceutical companies that produce (with at least some level of awareness) many drugs that quickly find their way into the illegal trade, airline and shipping firms that transport drugs, police officers who are on the payroll of drug sellers, a growing number of for-profit prison builders and managers who warehouse increasing numbers of (disproportionately ethnic minority) petty drug dealers (most of whom also are addicted to drugs) for financial gain, stores that knowingly (if unadmittedly) sell drug paraphernalia (like crack pipes and “cigarette” papers), diabetics who sell used or surplus syringes to street IDUs, suburban drug users who come to the inner city to buy drugs, and many others who contribute to the maintenance of street drug use and associated behaviors.

Missing from many past studies of drug users was a theoretical understanding that ties the street drug scene to this larger political economy, of which illicit drug consumption is but a small part. A critical understanding includes attention to what Mullings (1987) has called “vertical links” (like those listed above), which connect the social group under study to the larger society. Waterston, for example, has identified a number of economic roles of street drug users in the larger economy. She notes: “As a special category, addicts are politically weak and disconnected from organized labor, thereby becoming a source of cheap, easily expendable labor. Moreover, the costs of daily reproduction are absorbed by addict-workers themselves . . .” (Waterston 1993, pp. 241-242).

These same kinds of issues are important in understanding AIDS prevention. An analysis of structural barriers to the effective functioning of operational syringe exchange programs in three cities, for example, suggests that AIDS prevention programs are subject to numerous political, economic, and other social threats that diminish their capacity to limit the spread of AIDS (Heimer et al. 1997).

While anthropology brings several strengths to the field of drug studies, its capacity to develop a unifying theory has been hindered by fragmentation within the discipline (Goodman and Leatherman 1998). For much of its recent history, biological anthropology, the branch of the discipline most concerned with human evolutionary biology, has attempted to bracket the role of political economy in

shaping human health, on the grounds that this topic raises issues beyond its subdisciplinary purview. As Goodman and Leatherman (1998, p. 15) note, “What [Debra] Martin [has said] . . . for skeletal biology—that the laboratory blinds were pulled down to avoid contact with an external reality—generally applies to other areas of biological anthropology.” In analyzing environmental change, adds Wiley, biological anthropologists

tend not to explore research questions about *why* the environment was disrupted, by whom, and for what ends, but instead focus on the process of responding to or coping with such disruptions . . . This focus steers researchers away from contemporary social ills such as inequality and maldistribution of resources and power differentials, which are couched in such terms as “culture contact” and “modernization.” Instead of factors originating in social forces, “culture contact” or “diseases of modernization” are put forth as stresses, while the roots of these forces remain unexamined (Wiley 1992, pp. 223-224).

Why might such fundamentally important issues remain unexamined? One answer is that “the problematic of science—what questions are thought to be worth asking and what priority will be awarded them—is strongly influenced by social and economic factors” (Levins and Lewontin 1985, p. 4). At any historic moment, “What pass as acceptable scientific explanations have both social determinants and social functions” (Lewontin et al. 1984, p. 33), although countervailing voices can also be heard (e.g., Goodman and Leatherman 1998). Even methodologies exist in politicized space. Writing from within the realm of National Institutes of Health-funded medical school research, for example, Price (1992, pp. 136-137) notes that “To the degree that anthropology is associated with qualitative methods, it is regarded as a second rate social science.” Although this is less true in drug research, even the relatively long and productive history of ethnographic study of street drug use (e.g., Agar 1973; Atkins and Beschner 1980; Feldman 1979; Hanson et al. 1985; Preble and Casey 1969; Singer, this volume, “The Ethnography of Street Drug Use Before AIDS: A Historical Review”; Wepner 1977) has not completely secured its place as a fully legitimate methodology. Concrete contributions to prevention and intervention, including translation of ethnographic insights into specific and testable programmatic strategies in the drug field, offer a

route for overcoming the fact that ethnographic research remains “low on the scientific pecking order” (Stimson 1995, p. 757).

## CONCLUSION: TOWARD A CRITICAL BIOCULTURAL MODEL

This chapter argues for a paradigmatic shift based on a thoroughgoing synthesis of politicoeconomic, social, cultural, and biological information on substance use and disease transmission and risk. Rooted in a socially aware street ethnography that situates microcontexts and on-the-ground behaviors within a wider politicoeconomic structure and a holistic anthropology that focuses on humans as biocultural beings, this theoretical perspective, termed “critical bioculturalism,” views drug use and related disease risk as inseparable components of a complex syndemic of interlocked biological and social threats to well-being. From the perspective of critical biocultural theory, inner-city drug use and AIDS, STDs, TB, and hepatitis are most productively studied not as simultaneous or even as interacting epidemics but as parts of a *broader pathosynergistic process* that unites (1) oppressive social conditions/relationships and their associated culturally shaped behavioral responses (e.g., sharing syringes because of the socially imposed shortage of sterile syringes available to drug users in many locales), (2) a set of physical and emotional diseases of poverty, and (3) numerous comorbid biological and biosocial interactions (e.g., between diet and disease, behavior and infection, illicit drugs and disease progression, emotional state and immune response, viral lethality and ease of interhost transmission and among coexisting pathogens).

As Mann and colleagues (1992, p. 3) argue, “The global [AIDS] epidemic is composed of thousands of smaller, complicated epidemics.” Within each local setting, the factors listed above combine in unique ways to shape the AIDS epidemic among drug users. For example, an analysis of five cities—Glasgow, Scotland; Lund, Sweden; Sydney, Australia; Toronto, Canada; and Tacoma, United States—found that three factors appeared to be especially important in keeping seroprevalence among drug users lower than 5 percent: (1) implementation of HIV prevention efforts while seroprevalence is low, (2) provision of sterile injection equipment (e.g., through syringe exchange programs), and (3) community outreach to IDUs (Des Jarlais et al. 1995). By contrast, researchers in Hartford found that HIV seroprevalence approached 50 percent among IDUs from the time when community outreach began and the

provision of sterile injection equipment without a prescription was banned by law until after the epidemic was already 10 years old (Singer et al. 1997). As a result, the multiperson reuse of syringes (i.e., “sharing”—because of a socially imposed shortage of sterile syringes available to IDUs—was more common in Hartford than in cities with low seroprevalence among IDUs (Singer et al. 1992).

In this light, critical biocultural theory suggests several areas of promising drug use and related health risk research:

1. Analysis of the politicoeconomic forces that shape on-the-ground (i.e., observable) risk behaviors (as opposed to the current focus on individual decisionmaking, self-assessed personal capacity, and knowledge as the ultimate determinants of risk)
2. Study of risk behavior as a psychosocial response to an oppressive social environment characterized by harsh living conditions, violence, and unequal access to social opportunities and resources, including health care
3. Examination of pathosynergistic processes that connect disease transmission and progression with social conditions
4. Study of comorbidity in a social context

Each of these areas of research has important implications for drug use and disease prevention research as the field evolves over the next decade—from its roots in psychologically driven, individualized intervention to social intervention and prevention models based on an awareness of human biopsychosocial enmeshment in partnerships, families, and communities (Auerbach et al. 1994; Singer and Weeks 1996).

## **NOTE**

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# **Chapter 3. To Theorize or Not To Theorize: Anthropological Research in Drugs and AIDS**

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## **ABSTRACT**

Anthropology's atheoretical stance in its inductive approach to scientific inquiry has proven advantageous in its interactions with other disciplines. Transdisciplinary studies that involve anthropologists in solving research problems related to human behavior have benefited from contributions by coinvestigators whose disciplinary backgrounds form a complementary configuration of interests and capabilities. Specific examples of this complementary relationship include, for example, studies that characterize HIV contamination in the syringes of injection drug users, risk of mortality in coinfection, and the prediction value of immune markers. Theory related to anthropology's fundamental paradigm of culture has provided conceptual frameworks for studies of specific complexes of behavior. Large-scale initiatives funded by the National Institute on Drug Abuse provide numerous examples of successful applications of midlevel anthropological theory in studies that focus on HIV-related risk among drug users. Together, theories of culture change, cognitive domains in culture, and social structure have formed frameworks for research on risk of HIV infection and prevention of that risk. Both transdisciplinary studies involving anthropologists who take atheoretical approaches to inductive research and theoretically framed anthropological studies utilizing midlevel theories have made substantial contributions to knowledge about drug users and the consequences of drug use.

**Key words:** Transdisciplinary research, anthropological theory, cultural paradigm, midlevel theory, HIV risk and drug use

## **INTRODUCTION**

This chapter cites examples of research projects on drug use and acquired immunodeficiency syndrome (AIDS) that to varying degrees combine the capabilities of disparate scientific methods and

link them to health outcomes and other aspects of the human condition. The projects described here derive their strength from the cooperation of multiple disciplines. Most importantly for the issues of concern in this research volume, anthropological inquiry provides both specific information and overall guidance in the production of useful and theoretically relevant results.

Anthropological contributions to the study of drug use have taken two different forms: (1) the traditional, lone anthropologist who gathers predominantly qualitative data to improve our understanding of drug-using behaviors and (2) anthropologists who work as members of a team comprising scientists from various disciplines and who focus their attention on one set of research questions. The work presented in this chapter consists primarily of the latter variety of anthropological endeavor. Two approaches to anthropological research have dominated this type of inquiry: (1) theory building, or “atheoretical” approaches, and (2) approaches that develop and apply midlevel anthropological theory. The following discussion provides explanations and examples of both kinds of anthropological inquiry, pointing out their contributions to the literature on drug use and highlighting the contributions of the National Institute on Drug Abuse’s (NIDA) Cooperative Agreement Program, especially in terms of midlevel theory.

## **THEORY BUILDING (ATHEORETICAL APPROACHES)**

In many fields, specialization among scientific disciplines has led to intensive elaborations of highly specific methods to extract information in minute detail on closely defined phenomena. In an age that has encouraged specialization, the disparate capabilities found among narrow fields of inquiry often work in isolation, fomenting their own bodies of theory, literatures, and orthodoxies. Much of the research conducted in medical schools, research institutes, and corporate research and development laboratories operates within well-defined boundaries of established disciplines. In the context of transdisciplinary research, however, highly developed but narrow disciplines can form synergistic relationships that reunify the laboratory result with the human condition. In this context, the anthropological approach to inductive research often uses an atheoretical, or theory-building, point of view.

The attempt to build theory while gathering data begins with the advantage of researcher openness to a wide variety of possible findings, but it has the disadvantage of seeming directionless. Inductive studies, whether conducted by sociologists (Strauss and Corbin 1990) or anthropologists (Agar 1986, 1996; Spradley 1997), start out with few assumptions about how the phenomena to be studied fit together in causal or other explanatory schemes. The lack of assumptions encourages the investigator to collect information and examples of the studied phenomena wherever and in whatever condition they may be found.

Not surprisingly, much of what the investigator collects may seem only tangentially related to the phenomena of interest, but this process allows the investigator to differentiate among the phenomena of interest and other phenomena. For example, in the study of needle use among injection drug users (IDUs), it became clear through participant observation that needle “sharing” was inadequate as a descriptive term for use of contaminated injection paraphernalia (Page 1990). By not accepting the term “sharing,” which had general acceptance among health researchers (Magura et al. 1989) before going into the field, it was possible for the investigator to identify more accurately the kinds of risky behavior that took place among IDUs. These behaviors included use of “pooled” syringes (syringes stored in a common receptacle such as a basket or coffee can) (Page et al. 1990a), transfer of drugs from syringe to syringe (Inciardi and Page 1991), use of common water containers (Page and Smith 1990; Page et al. 1990c), and “cookers” (receptacles used for mixing and heating a drug solution) (Page et al. 1990q). Sharing—in the sense of passing a used needle from one person to another—did not occur in any of the observational settings reported in these articles. Subsequent investigations by Koester (1994) and Jose and colleagues (1993) have supported the concept of “indirect contamination” by these and other means.

Atheoretical approaches to research on drug abuse predated AIDS research. Agar’s *Ripping and Running* (1973) provided a useful and highly instructive map of the process of “getting off” (alleviating the craving for more drug) through use of free listing and pile sorting techniques designed to discover the key components of self-injection behavior and array them in an emically logical sequence.

Somewhat later, atheoretical research took on interdisciplinary components in the study of cannabis use and its consequences

(Carter 1980; Rubin and Comitas 1975). Rubin and Comitas (1975) pioneered the participation of various disciplines in a single study of cannabis use in Jamaica, although the medical and sociocultural substudies recruited separate populations. Carter's (1980) research team conducted a study of the effects of long-term marijuana smoking in Costa Rica. Their research combined the strengths of several specialized disciplines to achieve a unified view of cannabis' effects through examining the health statuses and careers of a single group of long-term smokers. Two examples of interdisciplinary collaboration in this study include the following: (1) The psychometric component used as a framework for some of its analyses a typology of marijuana smokers developed by the anthropological component (i.e., assigning group membership according to the typology and comparing among groups for differences in personality profile), and (2) the anthropological component used findings of several other components in summarizing lifestyles of the study population (Carter 1980). Additional studies supported by NIDA focused on cognitive function and work performance (Fletcher et al. 1996; Page et al. 1988), but always maintained an interdisciplinary approach with attention to the cultural contexts in which the study participants lived. When the AIDS pandemic progressed to the point of general alarm, some of these investigators became involved in already active interdisciplinary efforts to understand how people incur risk of human immunodeficiency virus (HIV) infection.

The need for access to populations engaged in behavior that places them at risk also helped bring disparate disciplines together in response to the AIDS pandemic. Anthropologists who had received funding from NIDA to study street-based drug users became especially important in the effort to understand the epidemic among IDUs in terms of the kinds of risks incurred (Page et al. 1990a).

### **Transdisciplinary Study of HIV**

Risk of HIV infection among IDUs attracted attention in the AIDS literature, especially because once the source of immunosuppression was known (i.e., a retrovirus that spends much of its life cycle within the cell), it became obvious that prevention of exposure would have a better immediate chance of preventing disease than would a vaccine.

Interdisciplinary study of the nature of risk had left major questions unanswered regarding the state in which pooled needles and syringes (hereinafter referred to as "works") available to drug users in "safe

houses” (sites where IDUs can inject drugs in privacy and obtain syringes and other necessities for injecting) or “shooting galleries” (safe houses) pass from user to pooling container to user. Chitwood and colleagues (1990), on the strength of the observations of Page and coworkers (1990a), set out to determine how risky pooled works were. A field team collected works from several different “get-off” houses (Miami, FL, term for safe houses) and sorted them by appearance and functionality. The laboratory team developed a strategy to apply water to the syringes that still had operative plungers to obtain a sample from each syringe. Team members then tested the water that had been placed in the syringe for evidence of the HIV antibody by means of the highly sensitive enzyme-linked immunosorbent assay (ELISA). The result of this collaborative effort, which could be termed “transdisciplinary,” suggested plans of intervention that focused on the proprietors of get-off houses (Chitwood et al. 1990). Transdisciplinary research denotes several disciplines working toward a unified goal in which the product cannot be identified with any single discipline.

Among the investigations conducted pursuant to the study of serostatus in needles, viability of virus in needles and syringes demanded early attention. A molecular biologist and his staff (Shapshak et al. 1994) teamed with sociologists, an anthropologist, and a pharmacologist to investigate how effectively bleach neutralized active HIV in syringes. To frame experiments that resembled the behaviors of IDUs, the team relied on the observations of the anthropologist and the workers who conducted outreach for a large intervention study. The observations provided a basis for instructing the laboratory staff on what kinds of needles to test, how to expose the needles to HIV, and how to approximate the behaviors of the users in rinsing their works. Results from this study suggested that IDUs needed instructions on how long to hold chlorine bleach in the works to ensure neutralization of the virus. If the virus in the syringe had fewer than 30 seconds exposure to full-strength household bleach, the laboratory was able to culture viable HIV from that syringe. In syringes with exposures of longer than 30 seconds, the laboratory could not culture viable HIV. This result increased the specificity with which health educators could frame instructions to IDUs on cleaning syringes and other paraphernalia.

Pursuant to that study, the same team members (Shah et al. 1996) came together to conduct tests on the other paraphernalia used in injecting drugs. They found that the aluminum bottle caps used to

heat or dissolve heroin and cocaine, the filters through which the drugs are drawn into the syringe, the water used for mixing drugs, and the water used for rinsing all had detectable evidence of the presence of HIV. This research team had recognized a cultural context in which works were not the only possible vehicles for contagion. Furthermore, the testing of "clean" water, which is used only to mix drugs (Page et al. 1990a), also had demonstrable presence of HIV.

Similar collaborations have taken place in Connecticut, where Heimer (a virologist) and Singer (an anthropologist) have joined forces on two projects—one that evaluated the Hartford syringe exchange program (SEP) and one that studied the diffusion of benefits of SEPs (Heimer et al. 1997; Singer et al. 1997). Both studies included an assessment of contamination of syringes that had been marked with bar codes before distribution by the SEP. The first study (Heimer et al. 1997) analyzed syringes that were collected by the SEP, and the second (Singer et al. 1997) analyzed syringes that were collected in known injection locations in the community. These studies hold promise for advancing the understanding of how SEPs affect not only the risk of IDUs for HIV infection but also the risk found in the surrounding community environment, a continuation of work begun in 1991 on community context of risk (Singer et al. 1991, 1992). These investigators have also published work on the impediments to implementing syringe exchange (Heimer et al. 1996).

Recently, Page and Salazar (1999) found a widespread pattern in the mixing of heroin that capitalized on already established interdisciplinary cooperation. Whereas heroin users in the rest of the world dissolve heroin by heating and mixing it in water, heroin users in Valencia, Spain, mix it with two or three drops of lemon juice before adding water and injecting. This observation required the investigators to test the pH of the lemon juice solution and investigate the solubility of heroin compared with that of other opiates. The investigators were able to answer these questions rapidly, because a collaborating biochemist tested the pH and a collaborating pharmacologist found indices of solubility for various opium-derived drugs in the literature. The initial findings suggest further directions for the study of lemon juice and HIV risk. Lemon juice in the concentration usually found in Valencian drug doses produces a relatively high level of acidity ( $\text{pH}=2.77$ ), but because of the high solubility index of pure heroin (1.6 parts water to 1 part heroin), the juice appears to be necessary only to dissolve the

adulterants in preparation for self-injection. Additional studies will examine the processes of heating heroin and compare them with those of adding lemon juice to determine what impact they have on the viability of the virus. Additional considerations for future research will include determination of interactions between heroin and lemon juice and presence of pathogens in lemons reused by "chutadero" (the Spanish name for shooting gallery) clients.

### **Transdisciplinary Study of HIV Progression to AIDS**

Joint NIDA and National Institute of Mental Health funding of a multidisciplinary center for the study of AIDS provided a unique environment for development of transdisciplinary perspectives on HIV infection and its progression to AIDS. The Center for the Biopsychosocial Study of AIDS drew participation from a wide range of disciplines, including immunology, psychiatry, psychology, internal medicine, biostatistics, anthropology, sociology, social work, neuroendocrinology, nutrition, and pediatrics. At the suggestion of a pediatrician, Page and colleagues (1990b) investigated the seroprevalence of human t-cell lymphotropic virus type II (HTLV-II) in a cohort of IDUs and discovered that 23 percent of the cohort had HTLV-I or -II. Furthermore, on followup with those who were coinfectied, they found that a high proportion had died of AIDS. This accidental finding led to further analysis using proportional hazards modeling (a form of survival analysis), which indicated that coinfectied individuals were more than three times as likely to die in a comparable period of time than individuals with no coinfection (HIV alone). Subsequent studies of immune parameters among IDUs suggested that different conditions of retroviral infection were associated with different immune statuses (Klimas et al. 1993). These results led to additional investigations that combined monitoring of risk behavior, immune status, nutritional status, and health status.

Page and coworkers (1996) have used survival analyses to show that immunoglobulin G (IgG) is an important predictor of health outcomes in IDUs with HIV infection, in some cases overriding the importance of CD4+ cell counts. Detailed prediction of health outcomes among North American IDUs has received relatively little attention in the literature, but these and other studies clearly indicate that clinical approaches to AIDS patients who are IDUs need to anticipate responses to AIDS and immunosuppression that differ from those of AIDS patients who are not IDUs.

Behaviorally, IDUs who become AIDS patients have their own patterns of response to treatment and medication (Smith and Page 1996). In a study of 20 thoroughly characterized IDUs who had presented with AIDS-defining illnesses, the investigators took advantage of long-term, regular interaction with IDUs to examine how they gained access to treatment and medication, how they adhered to treatment regimens, and how they lost access to treatment and medication. Their most consistent sources for antiretroviral (reverse transcriptase-inhibiting) medications were prison infirmaries. Once the study participants were released from prison, they lost reliable access to these medications. Availability of data on blood levels of zidovudine, immune parameters, health status, and risk behaviors helped make this study possible, a product of ongoing collaboration of anthropologists with various other disciplines.

## THEORY IN ANTHROPOLOGICAL INQUIRY

A substantial volume of anthropological and other ethnographic theory forms a solid base for understanding not only single cultural traditions but also the similarities and differences between cultural traditions. These conditions are well established and have been well critiqued in the anthropological literature. Nevertheless, pragmatic classification of these theories can place them into five cultural themes and their accompanying critiques and dialectics. The theoretical discussions include:

1. Evolutionary theories that focus on the cultural parameters of “change through time”
2. Cognitive theories that promote the exploration of the relationships among thought processes, beliefs, emotions, knowledge, and so forth and the observable behaviors that individuals exhibit
3. Theories about the organization of human behavior beyond the individual level (e.g., kinship, social networks, associations)
4. Theories of human manipulations of symbols (e.g., symbolic anthropology, communication theories)
5. Theories that explore cultural-ecological relationships (biology and behavior interactions at multiple levels), including

relationships of humans to their biological and physical environments

The parallel development of consistently evolving ethnographic research methods—including “participant observation” and other multimethod, multitechnique approaches to ethnographic data collection—has enhanced these theories. Methodological developments have led to increasingly sophisticated definitions, systematic conduct, computer-assisted analysis, and practical application of enhanced methods (Agar 1986; Bernard 1988; Pelto and Pelto 1978; Strauss 1987; Weller and Romney 1988; Werner and Schoepfle 1987). Some of the NIDA Cooperative Agreement sites have presented an overview of their methodological work in the NIDA monograph *Qualitative Methods in Drug Abuse and HIV Research* (Lambert et al. 1995).

Key advances also have improved ethnographic sampling designs. Johnson (1990) provided the first thorough exploration of the similarities and differences between the probabilistic sampling used in surveys and experimental designs and the purposive sampling strategies necessary for successful qualitative research. NIDA’s Cooperative Agreement Program advanced these concepts for the multifocal research required for HIV and drug abuse intervention programs (Bluthenthal and Watters 1995; Carlson et al. 1994; Elwood et al. 1995; Siegal et al. 1993).

All of the midlevel theories described below assume that the qualitative sampling designs have been correctly constructed for the intent of the project and that the special conditions necessary for ensuring reliability and validity in ethnographic research have been accommodated.

### **The Cooperative Agreement Program as an Arena for Development and Application of Midlevel Theory**

One of the comprehensive examples of the use of successful ethnographic approaches to HIV risk reduction is found in the NIDA Cooperative Agreement Program. This program funded 23 sites (22 domestic and 1 international), which shared the common goals of establishing the epidemiological characteristics of active drug use in the United States, identifying the key characteristics of HIV transmission risks for active drug users, and testing the efficacy of locally designed HIV interventions against a nationally established

NIDA standard intervention (a combination of HIV counseling, testing, and information). From the beginning of the program, ethnographic research methods and theories were considered an essential part of the theoretical and methodological tools being applied to these issues. More than half of the Cooperative Agreement sites maintained an ongoing ethnographic research program as an adjunct to and an expansion of the psychosocial and epidemiological research methods that were also utilized within the Cooperative Agreement Program design.

The ethnographic research programs within the Cooperative Agreement sites utilized a diverse set of midlevel anthropological theories, which allowed them to

- Describe the cultural models of health and illness that provide a framework for understanding individual and group knowledge and beliefs about HIV infection and transmission dynamics
- Monitor both the stability and the change in drug use practices among different cultural groups
- Identify the key social contexts in which cultural beliefs and values are turned into action
- Establish the intervening conditions that either allow for change (protective forces) or prevent change (barriers) in risk behaviors
- Understand the cultural-environmental and the political economy of drug use, HIV infection, and the behaviors associated with risk taking in a broad sense
- Provide a theoretical framework for determining the decision making and sustainable actions of the group and identify the conditions necessary for sustained maintenance of behavioral change for individuals
- Identify the symbolic and communication conditions imposed by cultural systems that relate to health behavior and behavioral change
- Either initiate or restructure culturally competent and effective interventions at the individual and group levels

The Cooperative Agreement Program structure also facilitated multisite ethnographic research programs that followed the same data collection protocols, which could be more fully generalized across geographic regions and compared within and between cultures in different locations in the United States. These multisite ethnographic projects were extremely valuable in assessing larger social conditions and trends beyond the reach of single-site investigations. Each of these programs, projects, and processes was informed by both “grand” ethnographic theory and midlevel theories of cultural processes. The following sections summarize some of the theoretical constructs that were developed and tested within the context of the Cooperative Agreement Program.

***Midlevel Theory and the Cooperative Agreement Program.*** Several recent Cooperative Agreement Program studies exemplify the use of anthropological theory to assess change through time. Booth and colleagues (1993) provide a model for combining qualitative and quantitative measures of behavioral change in risk-taking behavior through time at the community level, whereas Singer (1996) provides an evaluation of programmatic change through time on HIV prevention issues. Elwood and Ataabadi (1997) present a complementary use of diffusion theory in evaluating the impact of radio public service announcements at the local level, compared with individual-level influence.

***Connections Between Internal (Cognitive) and External (Psychological) Approaches.*** Research on aspects of the internal-external connections between thought and behavior has developed predominantly within psychological anthropology and cognitive anthropology, although other approaches have also played a part in this area of midrange theory development. The midlevel theories that appear to be the most commonly used include the cultural models approach, cultural beliefs systematics, and cultural cognition (domain analysis). Specific examples of the use of a cultural model or cultural health beliefs model in the Cooperative Agreement sites include research on building culturally congruent prevention systems, which are more than models; they are structural programs that test the models (Weeks et al. 1996a) and gender-sensitive or congruent models for intervention programs (Weeks et al. 1996b).

Cultural domain analysis provides another arena within which midrange theories have been successfully applied to both research

questions and the development of HIV and drug interventions. These approaches represent excellent models for providing culturally competent, locally motivated information for HIV prevention, as in the case of a Puerto Rican study of what individuals wanted to know about substance abuse and AIDS education from risk-reduction programs. They can also provide key information for qualitative-quantitative bridges to find predictors of risk perception among female drug users (Singer et al. 1998) or explore the attitudes of active drug users toward needle sharing.

Systematic explorations of mental health and other illness domains can be pursued subsequently through the use of three interlocked cognitive anthropology methods, including (1) techniques for exploring the content and limit of cultural domains (e.g., free listings, sentence-frame completion, contrast sets); (2) techniques for establishing structural and cognitive relationships among the elements of cultural domains (e.g., pile sorts, dyad and triad tests, Q sorting, matrix profile analysis); and (3) techniques for establishing the cultural consensual framework for these systems of knowledge and belief (Trotter 1991, 1995; Weller and Romney 1988). These techniques are amenable to use in a standard pretest/posttest design to analyze changes in cultural models or cognition over time. Many of these techniques provide a format for systematic ethnographic rapid assessment. They also provide a methodological basis for bridging between ethnographic and standard survey or experimental (quantitative) research designs, since they are typically analyzed using both qualitative (description of meaning) and quantitative (cluster analysis, multidimensional scaling, correspondence analysis) algorithms. For example, Trotter and Potter (1993) conducted an HIV risk pile sort with Navajo teenagers, using a list of risks that had been generated in focus groups and ethnographic interviews with Navajo cultural consultants. The results demonstrated that the students were linking risks within bounded risk areas (e.g., drug risks, school risks, violence risks) and that the linkages between those areas were weakly associated. The models of risk for the teenagers were valuable in constructing HIV and other risk prevention programs. These techniques permit ethnographers to produce greater analytical breadth and depth of detail and make rapid-assessment ethnography feasible in ways that have not been possible before.

***Social Organization and Structure: Cultural Context Research.***  
The bulk of health-related research has focused on either individuals

and their attributes or population samples collected through probabilistic sampling procedures. Although these approaches have a number of strengths, their weaknesses are twofold. First, the cultural context of health problems is all too often ignored by individual-centered approaches. Second, people spend a significant portion of their lives within the context of small interactive groups, where their behavior may be affected as much or more strongly by the group than by any individual characteristic that they bring to the group.

Anthropological midlevel theory has been highly productive in establishing the importance of cultural contexts and the organization and structure of human systems. These approaches derive from theories of kinship and social network analysis and the impact of cultural structures on human behavior.

Ethnographic network mapping allows an ethnographer to describe the participants, behaviors, kinship and friendship ties, and consequences of small “bounded groups” (groups with clearly defined network links within a geographic area) in a community, through extensive qualitative interviewing at the community level. The composite ethnographic characteristics of the networks can be used to create a “drug network” typology or classification system and can describe the individual and group context of drug use (such as crack houses, local manufacturing and distribution, etc.). Cooperative Agreement researchers (Trotter et al. 1994, 1995a, 1995c; Williams and Johnson 1993a, 1993b) have demonstrated that this type of data is extremely useful for targeting intervention and education activities for the highest risk groups, based on multiple risk criteria. The data can also provide important information about the subepidemics that are likely to be part of drug use in network groups (Trotter et al. 1994; Williams and Johnson 1993b).

The NIDA Cooperative Agreement projects have tested some useful midlevel theories to identify network structural elements. These findings provide public health measures of HIV and drug risk conditions (Trotter and Baldwin 1995; Trotter et al. 1995b) as well as epidemiological comparisons of HIV risks within the personal network context in cities around the United States (Williams et al. 1995a, 1995b).

**Cultural Ecology, Critical Anthropology, and Cultural Epidemiology.** The midlevel theories related to cultural ecology, critical anthropology, and cultural epidemiology that are currently being tested by participants in the Cooperative Agreement Program include barriers to change research (environmental factors research), cultural congruency models (conflicts in belief and process), human-biological interactions research, comparative cultural models research, deconstructionist models, critical theory approaches, and studies of the political economy of health and illness (Hill 1991; Lambert et al. 1995; Singer and Baer 1995). Cooperative Agreement participants have provided a wide range of evidence for the effectiveness of midlevel theory in the areas of critical theory, cultural ecology, and HIV risk reduction. These range from more theoretical constructions (Singer 1994a), to models for application of the theories (Singer 1995) and the politics of HIV research (Clatts et al. 1994; Singer 1994b).

Observational studies—direct observation of behaviors to determine the impact of the environment on behavior—constitute the primary methodology needed to accomplish the research goals of ecological or critical studies. Some of these studies have targeted the results of prevention or behavioral change programs and culturally competent interventions in risk-taking behavior. A linked series of studies of needle-sharing and needle-hygiene practices supported by NIDA exemplifies midlevel theory combined with observational methods in a cultural ecological context. The component studies of this project focus on context-specific uses of injection equipment among IDUs in the United States, as part of HIV risk-reduction efforts for IDUs. Research that replicates and extends Page's work (Clatts 1994; Koester 1994; Page 1990; Page et al. 1990a, 1990c; Singer et al. 1991) explores both the meaning and the processes of injection drug use, needle sharing, and the public health consequences of drug paraphernalia laws (laws that restrict the possession of syringes that might be used for drug abuse). Later studies (Clatts et al. 1994; Koester 1995; Needle et al. 1996; Singer et al. 1995) explore in depth the microenvironmental consequences of needle hygiene and needle sharing. One example of the latter approach is the Needle Hygiene Project, conducted by the NIDA Cooperative Agreement Program (Koester 1994; Needle et al. 1996). These studies have led to changes in the recommended messages and training processes for HIV risk reduction among IDUs. Indepth qualitative methods, applied for sufficient amounts of time, allow researchers to achieve clear characterizations of how people interact and exchange key materials, such as drugs and the paraphernalia used to ingest drugs.

## CONCLUSIONS

Anthropologists and other qualitative investigators who maintain a holistic perspective on their objects of study can help achieve needed assignment of meaning through participation in collaborative research efforts. The introduction of the phrase “assignment of meaning” denotes the process in which teams of scientists are both cautioned and edified in their studies of human beings. Firsthand knowledge of behaviors in cultural contexts that affect biomedical measurements and outcomes improves the construction of experiments in the laboratory and improves the analysis of epidemiologic data.

Reciprocally, understanding biological processes and the likelihood of medical conditions that require care improves the qualitative behavioral scientist’s grasp of the human condition under study. This kind of interaction has the effect on the anthropologist of reframing the observation and interpretation of behavior. For example, findings of cognitive deficits related to HIV infection (Wilkie et al. 1990) add perspective on observations of behavior among HIV-infected people. A street hustler who shoots heroin may encounter increasing difficulty in hustling because of the neurologic sequelae of HIV infection. The anthropological observer of that person could benefit by knowing that the hustler is HIV positive and has cognitive test results normally expected from a person three times his age. Overall, the knowledge acquired from these different perspectives—anthropological and neurological—can lead to a practical understanding of the impact of HIV in naturally occurring behaviors.

In the effort to understand and prevent drug abuse and its consequences, such as HIV infection, anthropologists working as qualitative behavioral scientists have much to offer to transdisciplinary teams of investigators, and their nonanthropologist colleagues likewise have much to offer. Most importantly, however, transdisciplinary teams as a whole offer the fields of drug use and AIDS studies the opportunity to advance those fields in ways that monodisciplinary, multidisciplinary, or interdisciplinary teams cannot.

Transdisciplinary scientific teams address the conceptual interstices of problems that require attention from more than one scientific frame of reference. In implementing a transdisciplinary approach to a problem, team members begin to internalize their colleagues’ key paradigms, making hybrid paradigms of increased vigor and generalizability. The findings emanating from NIDA’s Cooperative Agreement Program exemplify this kind of vigor and generalizability

in aggregates of predominantly behavioral scientists. In that particular company of scholars, it is especially important to use the theoretical tools described in this chapter to speak to other behavioral scientists about progress in research. The anthropologist in a mix of bench researchers, whether he or she uses an atheoretical stance or one that employs existing theories, can encourage colleagues to think about the total human condition, and the colleagues can encourage the anthropologist to add specific considerations of subcellular processes, immunologic activities, or any number of other paradigms to his or her holistic perspective. In this kind of interactive context, participants' identities as practitioners of specific disciplines blur, and their collective capabilities increase synergistically. For anthropologists, this process has the added attraction of extending appreciation for the anthropological view into other sectors of scientific research.

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# **Chapter 4. Interdisciplinary Research on the Transmission of Blood-Borne Pathogens in Drug Injection Practices: Applications of Ethnography in Epidemiology and Public Health**

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## **ABSTRACT**

Transmission of viral pathogens such as HIV infection among injection drug users has been attributed to serial reuse of syringes. In addition, some subsequent studies suggest that the “sharing” of ancillary injection paraphernalia, such as “cottons,” “cookers,” and “rinse water,” might also pose a risk. This chapter describes the methods employed in the New York City/Denver Drug Injection Practices Study, a multisite, multimethod research project that integrated observational ethnography and laboratory virology to overcome longstanding limitations in the available epidemiological information about viral transmission in drug injection practices. Constructed as a case study, this chapter describes the research design that was employed in the study and shows how each of the three phases of data collection built on one another both methodologically and analytically. Among the key issues considered is the use of ethnography in understanding variability in behavioral practices. Finally, the chapter provides a discussion of the key theoretical concepts that underpinned the development of the study and that may have significance for future epidemiological research on high-risk drug injection practices.

Key words: Ethnography, virology, injection practices

## **INTRODUCTION**

Among the viral infections most commonly transmitted in the course of injecting illicit drugs are human immunodeficiency virus type 1

(HIV-1), hepatitis B virus (HBV), and hepatitis C virus (HCV) (Des Jarlais et al. 1989; Garfein et al. 1996; Hagan et al. 1991; Hahn et al. 1989). Spread of these infections has been attributed to multiperson use of syringes by injection drug users (IDUs). In addition, a number of studies have pointed to the potential risk of "sharing" ancillary injection paraphernalia (e.g., "cottons," "cookers," and "rinse water" [see glossary at the end of this chapter for definitions of these and other terms]), as well as practices such as "backloading" and "frontloading" that are used in dividing drug solutions (Grund et al. 1991; Jose et al. 1993; Samuels et al. 1991). However, most of the behavioral research that has been conducted on HIV transmission risk among IDUs has concentrated on the individual characteristics of the IDU. There has been little research on the role of the social and physical environments in injection risk practices. Moreover, the preparation of drugs for injection is a process requiring several procedures and separate pieces of paraphernalia, almost all of which are subject to considerable variation. These variations, and the actual mechanisms by which HIV might be transmitted within these variations, have not been systematically examined. Consequently, there is little basis for estimating the different risks of transmitting viral pathogens among the several different behavioral practices that have been subsumed under the general rubric of drug injection.

Acquiring a better understanding of the effects of specific drug injection practices on the viability of blood-borne pathogens is important in understanding the epidemiology of the spread of blood-borne diseases and is vital for the development of targeted interventions. Unfortunately, reliable and detailed information about drug injection practices is still quite scarce, largely because the kinds of detail needed are extremely difficult to obtain solely from self-report methodologies. Using the National Institute on Drug Abuse (NIDA)-funded New York City/Denver Drug Injection Practices Study as a case example, the objective of this chapter is to describe the development of a research design aimed at integrating ethnographic methods and laboratory research in the study of viral transmission in drug injection practices. The authors' research on IDUs shows that methods derived from social anthropology, specifically an ethnographic method known as participant observation, can be used to overcome the methodological limitations in existing research on injection risk. The chapter also describes the conceptual foundations from which these methodologies are derived,

particularly in relation to the potential contributions of social anthropology to public health research.

## OVERVIEW OF STUDY DESIGN

Research on communities defined only by members' involvement in an illegal and stigmatized behavior such as drug use faces two major difficulties (Sotheran and Clatts 1996). First, it is difficult to determine the representativeness of a necessarily limited sample from a universe with unknown characteristics and dimensions. That is, how can the researcher discern the basis of population variability and where the particular parts of a sample fit into it? These limitations of generalization from the "snowball" or convenience samples customarily used in community research are exacerbated in the study of IDUs, a "hidden" but internally varied population defined only by participants' stigmatized and illegal behaviors. A second problem facing studies of IDUs lies in the fact that these behaviors are kept hidden and often cannot be reliably examined under experimental conditions. As a result, specific aspects of the practices used to prepare and inject drugs are not known with the kind of specificity that is required to resolve key questions about the transmission of viral pathogens in drug injection practices.

Rather than simply regarding the multiple partial perspectives available on the hidden population of IDUs as a problem to be overcome, the research design used in this study made these perspectives explicit and counterposed them to gain greater control over sampling and greater specificity in understanding injection practices. The study design used a controlled comparison of New York City and Denver, cities selected for their contrasting structural characteristics (e.g., population density, relative openness of injection groups) (Sotheran et al. 1995) and background HIV seroprevalence. This design was used to address the problems of ecological description, universe definition and variability, and access, all within the limited timeframe available for a public health study. Operationally, the study was divided into four components: (1) community assessment process, (2) extended ethnographic observation, (3) street-based survey, and (4) laboratory simulations of viral viability and transmissibility. Each of the first three components built on one another both methodologically and substantively, with the general aim of acquiring the kinds of specific behavioral data needed to

inform the fourth component involving ongoing laboratory investigations of viral transmission.

### **Community Assessment Process**

The study began with an ethnographically oriented community assessment process (CAP) (described in more detail in Sotheran and Clatts 1996). There were two broad objectives of the CAP: to (1) identify community-level differences between research sites (New York City and Denver), particularly factors that might affect the structure and composition of IDU groups or factors that might affect injection practices, and (2) identify comparable subpopulations and microenvironments on which to focus subsequent ethnographic investigations.

Methodologically, these objectives were accomplished through the use of three strategically targeted types of semistructured interviews with members of the community, as well as informal participant observation of settings and social venues in which IDUs are known to congregate. Selection of interviewees in the CAP was purposefully stratified to acquire information from different types of sources in the community.

Interviews with individuals designated as having a systemic perspective (“systems” interviews) included, for example, members of the local department of health, workers in sexually transmitted disease clinics, local police precinct community affairs officers, directors of needle exchange programs, directors of social service programs, and representatives of other service organizations in the community. A central goal of these systems interviews was to collect all available sentinel information about the target population, such as health statistics, police reports, and utilization data from services such as outreach, drug treatment, and health care systems. The authors’ experience with this procedure has demonstrated that early contact with persons in these organizations is instrumental in acquiring institutional information from highly bureaucratized systems and identifying and facilitating rapid access to individuals within these institutions (“interactors”) who have direct contact with the target population.

A second type of CAP interview (“interactor interview”) involves those individuals, typically outreach workers, health services staff members, and intake personnel at detoxification, methadone, and

residential drug treatment programs, who may have direct contact with the target population. Prior experience with these kinds of interviews has demonstrated that these individuals can provide vital information about the kinds of services used by the population of interest; some understanding of factors that may represent barriers to services; and information regarding where, when, and how target groups can be accessed. In addition, many of these sources, particularly members of local community service organizations, are often able to make initial introductions to individuals within the target population.

On the basis of information gleaned from both systems and interactor interviews, a social and geographic topography of the community was constructed that focused on where and when members of the targeted groups could be located. Ethnographers then began conducting participant observation in these locations, using participant observation as a technique for recruiting a small sample of drug users for key participant interviews. As Agar (1996b, p. 120) has noted, "participant observation suggests that you are directly involved in community life, observing and talking with people as you learn from their view of reality." Adler (1990, pp. 96-112) has added that "in conducting participant observation, the researcher attempts to gain a quasi-membership role that permits them to participate in the routine practices" (Adler 1990, p. 99). Both of these definitions emphasize the utility of participant observation as a methodological tool for gaining access to poorly described "uncaptured" populations and for describing social interactions in the environments in which these interactions occur in everyday life.

Participant observation requires the researcher to locate the population under study and participate in the social life with sufficient intimacy that the ethnographer is able to observe routine behavioral practices. This contrasts with recruiting samples (often of unknown representativeness) of the target population, who come to the researcher to be studied, outside of the population's natural environment. This approach is characterized by the informal observation of routine events and interactions as they unfold in everyday life, observation of the structure and performance of everyday life, and descriptions of how participants explain, order, and interpret such events (see Carey and Smith 1992). Of particular importance in this process is the utility of participant observation for identifying geographic and temporal differences in daily routines that may have importance for understanding compositional differences

within the target population as well as differences in injection practices.

Information derived from informal participant observation was recorded in ethnographic field notes in which ethnographers described the social and behavioral patterns they observed. Ethnographic maps were constructed on the basis of these observational data and included drug distribution areas, areas where commercial sex work occurs, street hangouts, clubs, bars, and community drop-in centers. Specific attention was given to variation in the use of these locations by different groups of IDUs, including differences in ethnic composition, age distribution, sexual preference, types of drugs available, variations related to time of day or day of the week, and the general effects on the stability of these patterns in relation to such factors as weather or police activity. These data were used to identify different subpopulations of IDUs and the kinds of settings and other natural venues where they could be located.

Based on information from systems and interactor interviews and initial participant observation, a third type of CAP interview (key participant interview) was conducted among a small sample of active IDUs. Key participant interviews sought to tap into the informant's knowledge of the composition of the target population (e.g., age, ethnicity, sexual preference, type of sex work, involvement in different types of drugs, etc.) and how these factors might be reflected across various drug injection settings. Prior experience with this kind of procedure has demonstrated that these interviews provide rich detail about sociocultural differences that members of the community view as meaningful and important, as well as the linguistic forms in and through which these differences are signified.

On the basis of data collected in the CAP, a purposive sampling plan was developed to guide research in phase II of the study, in which systematic participant observation of drug injection practices was undertaken. Owing to the interest in acquiring comparative data at both the macrolevel and microlevel, specific attention in the development of the purposive sampling plan was given to constructing an observational sample composed of comparable subpopulations of IDUs across contrasting injection environments (e.g., indoor versus outdoor injection settings, public versus private injection settings, etc.). The research design was aimed at examining the influence of the environment at two levels: macroenvironment (city) as well as

the microenvironment (e.g., type of injection setting), thus providing the basis for examining the independent effects of contextual and situational influences on injection practices. For example, type of injection setting and type of injection group are often confounded in studies of IDUs, and this design provided the analytical basis for disentangling them.

### Ethnographic Observation of Drug Injection Practices

The next phase of the study involved the use of several different kinds of ethnographic methodologies, including participant observation, life history research, social network analysis, and time allocation studies. The analytical power of these discrete ethnographic methodologies—as tools for discovery in public health—and the validity and reliability of the data they yield derive from the opportunity to tailor and combine multiple ethnographic methods according to the nature of research questions, the time and scope of the resources available, and the substantive and theoretical interests of the researcher. Since the emphasis in this discussion is on the integration of data from participant observation in laboratory studies of viral transmission, this discussion focuses on this particular methodological tool.

A key goal of participant observation is to document routine social and behavioral practices in the physical environments in which these interactions occur in everyday life. As the “natural language” connotation implies, participant observation is exactly what it seems, a technique for conducting systematic visual observation of behavioral interactions. Perhaps less obvious, although highlighted in Agar’s (1996b) definition, participant observation is as much about the active processes of listening and talking as it is about the process of conducting visual observation. The participatory “immediacy” of the method involves active engagement on the part of the ethnographer, since seeing, listening, and talking are all interdependent components of that engagement. This requires an extended “ethnographic presence” in injection settings. Methodologically, the goal is for ethnographers to become so immersed in the daily life of the community that the presence of the ethnographer becomes part of the setting itself.

One of the key purposes of participant observation in this study was to acquire details about the complex process of injection. At a general level, the basic equipment used in drug injection includes a

syringe, a source of water (both to liquefy the drug and to rinse the syringe before and/or after injecting), a cooker (e.g., a spoon or bottle cap), sometimes a source of heat (matches or cigarette lighter), something to stir the mixture to break it up (often the back end of the syringe), and some kind of cloth-like material (cotton) to strain the mixture so that adulterants in the drug mixture will not be drawn up into the syringe. Since many of the most commonly injected drugs such as heroin and cocaine typically come in dry form (e.g., powder, granules, lump, rock, etc.), water (or some other form of liquid) is added to break down the drug into liquid form so that it can be injected. Typically, water is drawn out of a cup or small bottle and injected into the cooker and mixed with the drug substance. This liquefaction process is often facilitated by heating the drug solution, typically by applying heat from a match or cigarette lighter to the bottom of the cooker.

If the drug solution is being used by only one person, the next step is simply to inject the drug and then rinse out the syringe. If, however, the drugs were purchased by multiple IDUs by pooling their resources, as is often the case, then they must somehow divide the drug among themselves (Clatts et al. 1997; Sotheran et al. 1997). Since the quantities of drugs that are involved are often quite small, IDUs attempt to measure their share as precisely as possible. The easiest way of doing this is to liquefy the drug first and then divide it using the calibrations on the syringe to apportion shares. Once the drug has been liquefied, there are several options for dividing the solution among participants. One option is to share the syringe. Another option is to squirt each of the other persons' share of the solution back into the cooker so that each person can draw up a share using his or her own syringe, again using the calibrations on the syringe. IDUs do not favor this method since the person who draws up first can take a larger share. It also wastes some of the solution since it is not possible to draw all of the drug out of the cooker. Indeed, one of the principal reasons that IDUs retain injection paraphernalia such as cottons and cookers is because these materials are believed to contain residual amounts of drug solution that can be salvaged in the event that the user experiences drug withdrawal and is unable to obtain more drugs (Sotheran et al. 1997).

Another way to divide drug solutions is to backload or frontload them, rather than use the cooker for distribution. Backloading is accomplished by removing the plunger from another syringe and shooting part of the drug solution into the back of the barrel of

the recipient syringe (sometimes also called “piggybacking”). Alternatively, IDUs frontload solution by inserting the recipient syringe into the back of the donor syringe and drawing up the solution from the donor syringe.

After injecting, most IDUs rinse their syringes with water to flush out blood and adulterants in the drug mixture from the barrel of the syringe as well as the needle itself—materials that might otherwise cause the syringe to become clogged and unusable in the future. The water used is often drawn from the same container where water was drawn to mix the solution, and in many cases the rinse water is shot (injected) back into the water cup after rinsing the syringe. Typically, cookers, cottons, and the rinse water bottle are retained for the next injection episode, in which a different set of IDUs may be present, many of whom will also bring used injection equipment.

There are several potential sources of viral transmission in these interdependent behavioral practices, stemming from the fact that various pieces of injection equipment are used by more than one person, even if everyone uses his or her own syringe. For example, it is common for multiple IDUs to use the same cooker and cotton and to draw water from the same water container. Thus, the cooker, cotton, water, and syringe that are used for preparing drug solutions (and for measuring and transferring drug solutions) have been exposed to potentially infected blood products directly, or exposed indirectly to other injection paraphernalia that may have been contaminated by contact with infected blood products. The relative transmissibility of different blood-borne pathogens from different pieces of injection paraphernalia has not yet been determined (McCoy et al. 1998). Similarly, the mediating effects on the viability of particular viral pathogens from specific parts of the drug preparation process are unknown. For example, dilution with water and heating of drug solutions could affect both the viability of viral pathogens and their transmissibility.

Methodologically, participant observation was used to gain sufficient confidence of IDUs to allow access to the natural settings in which drug injection occurs. Analytically, participant observation was used as a means to map the potential passage of blood-borne pathogens in the course of drug preparation and injection and to systematically document variability in these practices. Emphasis was placed on collecting the following four specific types of information using participant observation.

**Material Culture.** The authors sought to establish a descriptive inventory of the material culture used to prepare and inject drugs.

**Environment.** Specific attention was given to conducting observations across a wide range of types of injection settings to enable comparing and contrasting drug preparation and injection practices in different kinds of environments. Analytically, this ecological comparison included both the macroenvironment (city) and the microenvironment (injection setting). For example, analysis of the macroenvironment showed that a major determinant of differences in drug-heating practices between New York and Denver are the different forms of heroin available in different regions of the United States, with “powder” heroin (a granular form) being dominant on the east coast and “tar” heroin (a brownish lump form) being dominant in the midwestern and western regions (Clatts et al. 1998b; Sotheran et al. 1995). Because it is easily dissolved in water, powder heroin is often not heated at all, and even when it is heated, it is heated only briefly. In contrast, tar heroin solutions, which are not as easily liquefied, need to be heated longer. These differences in heating practices have potential effects on the viability of viral pathogens in heroin-based drug solutions.

Similarly, study of the microenvironment showed that there are also within-city ecological differences, which are attributable to features of the microenvironment. For example, aspects of the physical features of public injection environments contributed to unsafe injection practices (Clatts et al. 1996). These features included inadequate light and lack of running water (which made it difficult for IDUs to practice adequate needle hygiene); high risk for discovery, interruption, or arrest (often necessitating rapid and less careful injection practices); and social pressure to share drug solutions or used drug paraphernalia with other IDUs.

**Role Specialization/Differentiation.** A misleading assumption about needle sharing is that there is a social equivalency among IDUs who are present at an injection event. In truth, there are distinct roles played by individuals in the process of acquiring, preparing, and injecting drugs and a relationship between these roles and distribution and control of risk in the injection process (Sotheran et al. 1997). For example, the authors found that roles in acquiring the drugs usually dictate who prepares them. In turn, the person who prepares the drugs is usually able to choose the method of dividing them. Methods of drug division can range from relatively safe

methods (e.g., splitting the drug while dry, as a powder) to three or four different methods of dividing the drug after it is in solution form. The most dominant practice, transforming the drug into solution form first and then dividing it as a drug solution, involves passing the drug solution through potentially contaminated syringes and auxiliary paraphernalia (cookers and cottons) in different sequences, with different potential consequences for transmission of pathogens from one piece of paraphernalia to another at each step in the process. In each of these steps, another potential source of contamination is introduced into the shared paraphernalia, with risk for the introduction of contamination increasing exponentially with each subsequent user. Thus, for example, IDUs who do not know how to inject themselves usually depend on other IDUs to prepare the solution and inject it into them. This is often associated with “sharing the shot,” a process in which the preparer is likely to inject first. Even if each participant has his or her own syringe, the person who injects first potentially exposes the cooker to contamination when dipping his or her syringe in to obtain the first share. Everyone who follows is exposed to any contamination that has been introduced. Dope-sick IDUs, or those who for some reason are unable to “cop,” are sometimes given the used cotton so that they may attempt to recover any remaining drug residue (a practice known as “beating the cotton”) and are thereby potentially exposed to any of the viral pathogens introduced by each preceding user.

**Technical Practices.** Finally, a major goal of participant observation is to compile a database to model variations in drug preparation and injection processes and simulate these variations in laboratory studies of viral infectivity. Several different kinds of observational data were collected. First, ethnographers documented the volumes of various substances that are used in the course of the drug preparation and injection processes, including dry drugs, water added (including its source), drug solutions drawn by each syringe, blood drawn into the syringe in the course of “booting” (registering a vein by pulling blood back into the syringe), and water and other liquids (such as bleach or alcohol) used to rinse the syringe.

Since blood-borne pathogens such as HIV are known to be heat labile, ethnographers also systematically documented whether drug solutions were heated and, if so, the length of time (measured in seconds) they were heated. Since the ethnographic inventory had identified the use of different types of cookers (e.g., spoons, bottle caps, soda cans, etc.) and since these different types of cookers

conduct heat at different rates, care was taken to collect observational data across a range of cooker types and different heat sources (e.g., lighter, matches, etc.). In addition to visual observation of the time duration that heat was applied in preparing drug solutions, a temperature validation substudy was conducted using a handheld infrared thermometer. Temperature validation measures documented variations in the actual maximum temperatures that were achieved in association with different heating practices (e.g., length of time heat is applied, type of heat source, type of cooker, volume of water). Using the same instrument, temperature validation studies were replicated in subsequent laboratory studies (see below), serving as the basis for examining the interaction among volume, heat source, cooker type, and heat duration with inactivation of different titers of HIV-1.

### **Street-Based Survey**

A structured survey instrument was developed with the overall goal of describing the prevalence, frequency, and distribution of specific injection practices that had been documented through participant observation. Ethnography was used in two fundamental ways in the development of the survey component of the study. First, following similar uses of ethnography in the development of targeted sampling strategies in out-of-treatment populations (compare Carlson et al. 1994; Clatts et al. 1995; Watters and Biernacki 1989; Weibel 1991), ethnography informed the development of the sampling plan that guided street-based recruitment for cross-sectional survey interviews. This ensured that the sample included a wide range of different types of IDUs in each city and also provided the basis for sampling comparable groups of IDUs in both cities.

Second, information derived from ethnography was used to inform the development of the analytic constructs used in the survey instrument, paralleling the interest in the prior observational studies of disentangling the independent effects on injection practices of both injection setting and injection group (Clatts et al. 1996; Zinberg 1984). Several of the broader constructs that are typically used in studies of drug users were broken down into a series of more detailed questions that were contextually relevant to the behaviors of interest and the communities being studied. For example, questions assessing housing stability included a range of different housing arrangements and types of housing stability rather than simply dichotomizing housing status into “homeless” and “nonhomeless.” This construct

reflected findings from ethnographic research that had revealed the fluid nature of housing arrangements among drug users and the need to acquire greater specificity in the form and stability in relation to drug injection practices. Similarly, constructs related to the process of dividing shared drug purchases were developed. These constructs were derived from the ethnographers' observations of actual drug-sharing practices and included language used by IDUs, thereby enhancing the validity of the construct.

### **Laboratory Studies of Viral Detection**

On the basis of parameters derived from observational studies, laboratory experiments were conducted to answer three general questions: (1) What specific injection practices might influence HIV transmission? (2) Is there a loss of viability of HIV-1 due to prolonged "storage" in a syringe or other injection paraphernalia such as rinse water and cottons? and (3) What is the relative loss of viability of HIV-1 in drug solutions that have been exposed to heat (cooking) in the course of drug preparation?

These questions were examined by adapting microculture assay techniques (Heimer et al. 1993; Heimer et al. 1996) to attempt to recover live virus from used syringes and related injection paraphernalia (e.g., cookers, rinse water, etc.) that had been inoculated with HIV-1. A proper simulation of injection processes required the use of a microculture assay because residual blood volumes with appropriate titers of HIV would contain too few virions for standard assays.

In modeling the experiments, particular emphasis was placed on cookers as a potential reservoir of viral pathogens (Hoffer and Anderson 1996), because, as described above, even in multiperson injection episodes in which each participant has his or her own syringe, cookers play a central role in preparing and dividing the drug solution among multiple IDUs. Moreover, even in single-person injection events, cookers have been used in previous injection episodes involving multiple, and often different, sets of participants. Thus, in the same way that IDUs bring used and potentially infected syringes to a new injection event, they also bring other potentially infected injection paraphernalia, which serves to potentially circulate viral pathogens between injection events and among overlapping injection groups (Clatts et al. 1998a).

Laboratory studies of injection practices involved introducing an inoculum of HIV-1 into particular articles of drug injection paraphernalia and submitting these paraphernalia to the kinds of effects observed in actual injection practices. This included modeling different types of injection practices (i.e., volumes of solution, type of cooker, use of heat, type of heat source, duration of heat). Researchers then sought to recover live virus from these materials to determine the potential effects of specific injection practices on inactivation of viral pathogens in various articles of injection equipment. Thus, on the basis of information derived from ethnographic studies of actual behavioral practices in the natural settings and groups in which they occur, laboratory simulations were used to better understand the nature of risk for viral transmission in real-world injection practices (Clatts 1998b; Clatts et al., in press).

## CONCLUSION: THEORETICAL UNDERPINNINGS OF ETHNOGRAPHY

This chapter describes a NIDA-funded study that used research methods from anthropology to advance the understanding of risk for transmission of viral pathogens such as HIV during drug injection. Ethnographic methods in epidemiological research among IDUs are important for several reasons.

First is the issue of *validity*. Although this chapter focuses on participant observation, ethnography is not a single methodology but rather a multipurpose set of complementary research methods. Like participant observation, most of these methodological tools are oriented to studying behavioral phenomena in the situations and contexts in which they naturally occur, requiring the researcher to interact with research populations on their own turf and usually in their own language (Kirk and Miller 1986). Thus, ethnography is a powerful tool for listening to the “voice” of the drug user and eliciting the IDU’s perspective on the behavioral practices and social processes of interest. This has descriptive utility in enhancing the validity of epidemiological categories and also is important in developing workable prevention messages and strategies.

Second, and perhaps most important in the context of the study described in this chapter, ethnography is a powerful tool for describing *variability*. Of particular note is the use of participant observation in understanding the types and sources of variability

in injection practices, many of which could not have been reliably established using alternative methodologies such as self-report. Thus, for example, even if researchers knew how to formulate a survey question about differences in the duration of drug-heating practices, it is unlikely that IDUs could provide reliable data on these practices. Without this kind of data, it is difficult to conduct the necessary clinical and laboratory studies needed to resolve fundamental questions about the transmission of viral pathogens in drug injection practices.

Finally, ethnography can make important theoretical contributions to research among drug users. The methodological approach that was employed in this study was grounded in four central theoretical concepts that underpin anthropological research. First, attention is given to material culture, used here, for example, in the form of a descriptive inventory of all the various material objects that IDUs use to prepare and inject drugs. Second, researchers note the variability in the technical practices IDUs employ to prepare and inject drugs, including the technical knowledge of how and where to obtain drugs and drug injection paraphernalia, how to transform drugs into injectable forms, and how to inject. Third, attention is paid to role specialization and differentiation. This was manifest in the manner in which researchers mapped the role-governed processes of drug acquisition and preparation, showing their significance for understanding sources of control over the injection process and the distribution of exposure risk within these processes. Fourth, and perhaps most important, is the attention given to understanding the effects of the physical and social environment. As Agar (1996a, p. 197) has noted, "Drug users have intentions and participate in learned conventions that guide their actions" (see also Zinberg 1984). These conventions are responsive (adaptive) to complex interactions with the physical and social environments (systems), and hence, both vary and change in relation to emergent situational and contextual features within the environment. Ethnography is a tool for describing the interaction between host and environment and for building synthetic models of the diverse and complex variables that influence the social course of blood-borne diseases such as HIV infection.

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## APPENDIX. GLOSSARY

**Backload (verb):** To transfer a shared drug solution among multiple IDUs' syringes. Backloading involves removing the plunger of the recipient's syringe and squirting the drug solution from the donor's syringe into the barrel of the recipient's syringe. Backloading is also sometimes referred to as "piggybacking" (see below for definition of "frontloading").

**Bag (noun):** A small plastic bag containing a drug substance in dry form. Typically the smallest unit in which powder heroin is sold.

**Beat a cotton (verb):** To resaturate a used "cotton" with water in an effort to recover any residual drug substance that may have been left after its use in a previous injection.

**Boot (verb):** Generally, to insert the syringe and then pull on the plunger to see whether blood is drawn back into the syringe. This is done to ensure that the needle has been properly entered into a vein rather than a muscle. Sometimes IDUs also refer to "booting" in relation to the practice of filling the syringe with blood, withdrawing the syringe and hand-shaking the drug solution and blood so that they are thoroughly mixed, and then reinserting in the vein and injecting. Sometimes referred to as "gravy" or "making gravy" and done in an effort to counteract the risk that the concentration of drug will be too strong.

**Cooker (noun):** Typically a spoon, metal bottle cap, or the bottom end of a soda can, a cooker may be any type of small vessel used to mix a drug substance such as heroin with water and thereby transform it into soluble form so that it may be injected. These vessels are called cookers because some IDUs heat the solution as a means of aiding the transformation of drugs into soluble form. Also, many IDUs believe that heating drug solutions ("cooking") helps remove any adulterants or particulates that may otherwise cause the syringe to become clogged.

**Cop (verb):** To purchase illicit drugs, particularly heroin.

**Cotton (noun):** A piece of fibrous material, such as a small piece of cotton, a napkin, a piece of cloth, or a cigarette filter, that can be used to strain particulates out of the drug solution so that they are not drawn up into the syringe.

**Cut** (noun): Some type of adulterant or filter that is added to a drug such as heroin or cocaine before it is sold to a user. Cuts add to volume that can be further divided into more bags, thereby increasing the number of units sold. In addition, to enhance the perceived potency of the drug, cuts also may be added that will mimic or enhance the expected pharmacological effects of the drug. Thus, barbiturates are commonly found in heroin, and amphetamines are commonly found in cocaine.

**Dime bag** (noun): Typically the smallest unit of heroin or cocaine available in a local street market, this is a quantity of drug valued at approximately \$10. Both quantity and cost may vary by region or in relation to periodic fluctuations in supply.

**Frontload** (verb): To divide drug solutions, by at least two somewhat different methods of transferring shared drug solutions among multiple syringes (e.g., see above for definition of “backloading”). One form of frontloading is simply the reverse of backloading. This involves removing the plunger of the donor syringe and drawing up the drug solution out of the back of the donor syringe into the front of the recipient syringe. In other usages of this term that are more common among IDUs employing very heavy gauge syringes, particularly in Southeast Asia, frontloading is used to describe a process in which the needle of one syringe is removed and the needle of another syringe is inserted into the front of the barrel, and the drug solution is transferred from one to the other in this manner.

**Needle sharing** (noun): A somewhat misleading term that is used to refer to the practice of serial reuse of a syringe by multiple IDUs. Serial reuse of syringes among IDUs does not necessarily involve any social or cultural foundation, as the word “sharing” might otherwise seem to suggest. Rather, needle sharing is best understood as a consequence of the fact that legal restrictions in accessing sterile syringes create a scarcity of syringes and other injection paraphernalia, a fact that serves to encourage retention and reuse among IDUs and that accounts for the excess prevalence of a number of viral pathogens such as HIV, HBV, and HCV among IDU populations.

**Powder heroin** (noun): Typically found in the eastern United States, this is a form of heroin that has been thoroughly refined. It typically has a powder or granular consistency, is light tan or white in color, and is sold in a small plastic bag.

Rinse water (noun): Generally any source of water used in the process of preparing and injecting drugs. The term is derived from the practice of drawing up water to rinse out a syringe either before or after a syringe has been used. Typically water is drawn from the same source to add water to the drug substance in the cooker and make it soluble.

Score (verb): To purchase illicit drugs, particularly cocaine.

Social network (noun): A term used by researchers to refer to both a set of people and the sum of the linkages among them in a defined population. Embedded in the social network are smaller webs of individuals involved in various kinds of cooperative activities. Groups confined to cooperative activities related to the purchase and use of drugs are sometimes called “drug networks” or “injection networks.”

Step on (verb): Illicit drugs such as heroin and cocaine are typically “cut” with adulterants at several stages in the process of refining them and distributing them for sale to a user. At each stage in the distribution process, drugs are “stepped on” (i.e., mixed with an adulterant) in an effort to increase the volume of units that can be divided and sold.

Tar heroin (noun): Typically brought into the United States from Mexico and predominantly found in the western part of the United States, this form of heroin is dark brown in color and gummy in consistency. Usually purchased in a unit referred to as a “pill,” a form of heroin that has not been thoroughly refined (compare with powder heroin above).

Works (noun): Generic term used to refer to multiple articles of paraphernalia needed to prepare and inject drugs, particularly syringes.

# **Chapter 5. Complexities in the Lives of Female Drug Users in the AIDS Era: Linking Ethnographic and Epidemiological Approaches**

*Claire E. Sterk*

## **ABSTRACT**

The largest increase in HIV infections in the United States is among women, and most of these infections are related to drug use. Although epidemiological studies provide insight into the demographic and geographic distribution of HIV/AIDS, such research does not explore the meaning of HIV risk behaviors or the context in which these occur. This chapter focuses on the gender-specific aspects of HIV risk taking among female drug users. Between June 1992 and March 1996, indepth interviews were conducted with 259 female drug users in Atlanta, GA. Additional information was collected through participant observation and structured interviews. The two sampling strategies involved targeted and theoretical sampling. Data analysis for the quantitative data included descriptive statistics, and grounded theory guided the qualitative data analysis. The findings focus on the dynamics surrounding "sex under the influence" and the impact of the women's social networks on their HIV risk taking. The chapter also addresses methodological issues concerning the integration of epidemiological and ethnographic approaches. The integration of these methods not only will increase the understanding of HIV risk-taking but also will allow for the development of gender-specific prevention and intervention programs and policies.

Key words: HIV/AIDS, female drug use, methods

## **INTRODUCTION**

Since the onset of the acquired immunodeficiency syndrome (AIDS) epidemic, the field of substance abuse has received increased attention. Because the early cases of AIDS were identified among men who have sex with men, AIDS initially was viewed as a "disease

of men." However, this initial label was modified as it became clear that human immunodeficiency virus (HIV) infection occurred among individuals who did not fit the original profile. Injection drug users (IDUs), women who exchanged sex for drugs, sexual partners of infected individuals, and children born to infected mothers also were vulnerable to HIV infection. In June 1996 the Centers for Disease Control and Prevention reported that 45 percent of the cumulative female AIDS cases were related to the women's injection drug use. An additional 39.3 percent were related to heterosexual transmission (Centers for Disease Control and Prevention 1996). The AIDS epidemic among women reveals the importance of exploring drug use, sexual behavior, and the relationship between them.

Drug use is a complex behavior that often varies depending on the type of drug used, route of administration, setting in which it occurs, and people with whom one uses, including their attitudes, behaviors, norms, and values. Drug use has been studied by experts representing a multitude of fields, for example, sociology, psychology, epidemiology, psychiatry, and anthropology. In the United States, several ongoing, large-scale epidemiological studies on drug use are being conducted. The National Household Survey on Drug Abuse is a cross-sectional survey involving multiprobability samples (Substance Abuse and Mental Health Services Administration 1996*b*), and the Monitoring the Future Study (Johnston et al. 1994) includes sequential cohorts of high school students and young adults. Other large-scale surveys are conducted among institutional samples (e.g., the Drug Abuse Warning Network [Substance Abuse and Mental Health Services Administration 1996*a*] in emergency rooms and the Drug Use Forecasting study [National Institute of Justice 1997] among recent arrestees). These and other epidemiological surveys provide insight into factors such as the geographical distribution of drug use and individual characteristics of users such as age, gender, and race/ethnicity.

Large-scale epidemiological surveys often receive attention by policymakers and the media, thereby influencing the public's knowledge of and attitudes toward drug use. When drug use decreases, policymakers, researchers, and others proudly declare that law enforcement, drug treatment, and behavioral interventions have been successful. Upward trends, on the other hand, frequently are used to challenge current policies and question the investment of public funds in services for drug users.

Sexual behaviors are at least as complex as drug use behaviors. Unfortunately, trend data on sexual behaviors are limited. Kinsey and colleagues (1948, 1953) were the first scholars to conduct a large-scale study of sexual behaviors. Their findings often are used as baseline data for subsequent studies. However, it is generally accepted that the Kinsey research had limitations. Other well-known surveys of sexual behaviors are the Playboy Foundation study (Hunt 1974), the *Redbook* survey (Travis and Sadd 1977), and the Couples Study (Blumstein and Schwartz 1983). The findings of these and other studies tend to be limited to topics such as frequency of sexual activity by gender or during the life span, type of sexual encounters, extent of extramarital affairs, and ratings of satisfaction with sex and marriage.

Whereas large-scale quantitative studies provide numbers and trends, such findings do not suggest why people behave the way they do and why changes may occur. The nature of epidemiological findings does not allow for an understanding of the complex behaviors surrounding drug use and sex suggested in the following questions: Why do IDUs continue to engage in HIV risk behaviors despite the threat of acquiring a deadly disease? Why do pregnant women continue using drugs instead of seeking drug treatment? Why do individuals engage in sexual acts they dislike? Answers to these and other questions are more likely to be generated by ethnographic research. The combined use of epidemiological and ethnographic approaches yields both the data and the explanations of human behavior. Public health professionals have come to believe that knowledge of underlying norms, values, and attitudes is necessary to understand individual and group behaviors (Feldman and Johnson 1986; Herdt and Lindenbaum 1992; Janes et al. 1986). For example, early in the AIDS epidemic, the "sharing" of needles and its ritual value among insiders were identified as the main risk factors for the spread of HIV among IDUs (Des Jarlais et al. 1986). However, subsequent research indicated that needle sharing may be due to economic constraints and the legal repercussions of carrying a syringe (Koester 1994). In general, ethnographic studies have contributed in significant ways to understanding the lives of drug users, development of drug use careers, various social roles and associated behaviors found in the drug scene, and the meaning of the language used (Agar 1973; Biernacki 1986; Bourgois 1995; Koester 1994; Page et al. 1990; Preble and Casey 1969; Stephens 1991; Waldorf 1973; Waldorf et al. 1992). Most early ethnographic studies focused on heroin and IDUs. However, as the crack cocaine epidemic began dominating the drug

market in the 1980s, the focus shifted to users of this substance (Inciardi et al. 1993; Ratner 1993; Williams 1992).

Few ethnographic researchers have explored the experiences of female drug users (Rosenbaum 1981; Taylor 1993). Moreover, the need for gender-specific studies was acknowledged by few researchers, and those who did focus on women often emphasized their involvement in prostitution activities (Goldstein 1979). More recently, others have limited their research to women's reproductive role and discussed the potential tension faced by female drug users, many of whom were also mothers (Kearney et al. 1994; Lieb and Sterk-Elifson 1996).

Studies on drug use among women have become more common since the emergence of the AIDS and crack cocaine epidemics. The exchange of sex for crack now is a well-studied phenomenon (Inciardi et al. 1993; Ratner 1993; Sterk 1988; Williams 1992).

Research has shown that many women who do not inject drugs are the sex partners of male IDUs and that a substantial number of these women use crack (Deren et al. 1993; Tortu et al. 1994).

Research exploring the links among drug use, sex, and HIV risk also reveals the need for a perspective that includes the impact of larger social forces such as racism, sexism, and classism (Connors 1996; Farmer et al. 1996; Singer 1994; Sobo 1995). Thus, HIV risk taking among women, whether it is drug or sex related, can best be understood when structural and gender inequalities are taken into consideration.

As knowledge of potential links among drug use, sexual behavior, and HIV risk increases, many questions are being answered, but new questions arise. Initial research on such links tended to focus on individual risk factors. Subsequent research, however, shifted to individual behaviors in sociocultural contexts and to social network approaches. The combination of methodological approaches also has become increasingly common (Lambert et al. 1995). This chapter explores the gender-specific aspects of HIV risk taking among women, including methodological issues addressing the integration of anthropological approaches in epidemiological and prevention research.

## METHODS

Data were collected in the Atlanta metropolitan area between June 1992 and March 1996 among 259 female drug users. To be eligible for the Female Atlanta Study (Project FAST), women had to reside in the Atlanta metropolitan area, be 18 years of age or older, and be active drug users who were out of treatment and noninstitutionalized. Women were recruited through contacts among drug users that had been established during previous research and with the assistance of community consultants. The latter were indigenous outreach workers who were familiar with the study communities. Potential respondents were asked to participate in a brief street interview and, if eligible, were invited for a longer indepth interview. Participation was voluntary, respondents were paid, and no personal identifiers were recorded.

Data were collected using various strategies, including participant observation, close-ended interviewing, and open-ended, indepth interviewing. Geographic locations for the participant observation were selected using ethnographic mapping and information provided by the community consultants. Participant observation was conducted throughout the project period in neighborhoods known as drug-copping zones where drug selling and using were visible and in neighborhoods where drug use was as prevalent but more hidden. As knowledge and understanding of the various drug scenes increased, the observations became more focused. In addition, the observations were guided by comparing field notes taken by the various observers. Conflicting observations were explored to identify possible observation bias or actual differences.

Interviews were conducted at a variety of locations, ranging from a downtown university office to various community settings. Targeted sampling was used to recruit women (Watters and Biernacki 1989). As the study progressed, theoretical sampling was added to the recruitment process (Glaser and Strauss 1967). Prior to conducting interviews, women were asked to sign an informed consent document. The interviews, which were tape-recorded and transcribed, ranged from 1½ to 4 hours. Interview topics included family history, reproductive history, drug use and sexual behaviors, drug treatment history, violence and abuse, health history (including AIDS), and social support. Close-ended questions were asked regarding similar topics following the Addiction Severity Index (McLellan et al. 1985). Egocentric social network data were gathered using a matrix.

The data collection and data analysis occurred simultaneously. Almost immediately after data collection, the data were analyzed by searching for salient issues and contradictions. Findings from all participant observation field notes and indepth interviews were discussed by the research staff members. Discussion focused on the validity and reliability of the information. These discussions were recorded in memorandums (memos), and distinctions were made among data collection memos (what needed to be explored further), methodological memos, and analytical memos.

Data also were analyzed by social network, and findings among networks were compared. This process showed the heterogeneity of female drug users and the importance of distinguishing among women who used in anonymous settings attended by multiple users, women who used in semiprivate settings in the company of a limited number of users, and women who only used with one partner in a private setting. Findings indicated the existence of various cultural models of drug use among female drug users.

## FINDINGS

### Brief Sample Description

The women included in Project FAST represented a cross-section of racial and ethnic backgrounds: The majority were African Americans, 25 percent were white, and another 15 percent were Hispanics, mainly Mexican Americans and Puerto Ricans. The women's ages ranged between 18 and 61 years, with a median age of 32. Nearly one-half of the women had not completed high school; the rest had graduated or had received a general equivalency diploma. Among these, one-half had completed some education beyond high school. Three-fourths of the women had at least one child; the remaining one-fourth were childless at the time of the interview. Slightly more than one-half of the women self-identified as primarily crack cocaine users, one-third as having shifted from primarily injection drug use to crack cocaine use ("shifters"), and the rest as primarily IDUs. Lifetime alcohol use was reported by the majority of the women, with two-thirds reporting alcohol use during the 90 days prior to the interview. Lifetime and past 3 months marijuana use was more common among crack cocaine users and shifters than among IDUs. The lifetime use of amphetamines was higher among IDUs and shifters than among primarily crack cocaine users.

## **Sex Under the Influence**

Certain sexual activities such as having unprotected sex with multiple partners and not using a condom with steady partners have been identified as risk behaviors for HIV infection. Research on the general population has shown that sexual behaviors are often difficult to understand because an individual may have several motives for engaging in sex, ranging from the confirmation of feelings of love, to economic reasons, to expressing power over a sex partner. Several women in this study indicated that they engaged in sex to motivate their male partner to consider a long-term, preferably monogamous, relationship. A number of women had a steady partner, whom they knew also often had sex with other women. This led to feeling ambivalent about having sex with him or proposing the use of a condom.

The women in Project FAST were asked about their drug and sexual behaviors. Their responses indicated that using drugs and having sex often were linked. Many women engaged in sex within 1 hour after having used drugs. Table 1 presents these data.

**TABLE 1 Sexual Activity Within 1 Hour After Drug Use (N=259)**

| Drug      | Percentage of women who had sex within 1 hour after use |
|-----------|---|
| Alcohol   | 76.0  |
| Marijuana | 69.6  |
| Heroin    | 48.8  |
| Cocaine   | 68.4  |

The women's responses indicate that alcohol use within 1 hour before sexual activity was most common, followed closely by marijuana and cocaine use. Sex within an hour after heroin use was much less common. The women explained that this was largely related to the psychopharmacological effects of heroin, a state some refer to as "mellowing out." A number of women explained that the effects of marijuana use made it an ideal drug for enjoyable sex, with fewer

inhibitions, but other women disagreed and indicated that marijuana use caused them to be less interested in sex. Typically, they smoked marijuana more often and in larger amounts.

Research exploring alcohol use and sexual activity has not shown a causal link between these two behaviors (Leigh and Aramburu 1996; Leigh and Stall 1993). Despite the inconclusive findings, research demonstrates that alcohol use is a marker for high-risk sexual behavior.

Since the emergence of the crack cocaine epidemic in the mid-1980s, the link between crack use and sexual activity has been explored extensively. Cocaine, including crack cocaine, is known to be a sexual stimulant. In addition, researchers have shown that female crack cocaine users often engage in sex as a means to support their habit (Ratner 1993; Williams 1992). Sex-for-crack exchanges also were common among the crack-smoking women in Project FAST. In the words of one woman: “A woman always has her (\*\*\*\*). It’s a lucky thing, but I’m telling you, it also screws me up . . . I can’t respect myself no more . . . The guys know it, too. They just wait for a woman to be really wanting a hit. Crack is not killing women; it takes the spirit out of them.”

In addition to elaborating on the prevalence of sex-for-crack exchanges, this woman also hints at the gender differences between men and women. Women are forced into a submissive role, while men tend to occupy dominant roles.

When asking the women in this study about the possible link between drug use and sexual activity, their first reaction was to describe HIV risk behaviors. They discussed the extent to which drug use caused them to be less selective with sexual partners. Drug use led them to not propose condom use, even if the partner was a man they did not know or if he proposed high-risk sexual acts. Many referred to “freaking,” which includes engaging in uncommon sex acts such as sex with other women, sex with multiple partners at one time, and anal sex. The women spoke of the relative importance of various drugs for these high-risk sexual behaviors. Their responses are summarized in table 2.

**TABLE 2 Percentage of Women Who Engage in HIV High-Risk Sexual Behaviors by Type of Drug (N=259)**

| Drug      | Less careful in selecting sex partner | Less likely to use a condom | More likely to engage in "freaking"* |
|-----------|---------------------------------------|-----------------------------|--------------------------------------|
| Alcohol   | 49.0                                  | 48.5                        | 46.4                                 |
| Marijuana | 25.0                                  | 39.6                        | 26.6                                 |
| Heroin    | 33.8                                  | 32.4                        | 33.8                                 |
| Cocaine   | 53.0                                  | 46.5                        | 50.5                                 |

\*Engaging in uncommon sex acts such as sex with other women, sex with multiple partners at one time, and anal sex.

Although cocaine ranks highest in terms of causing women to be less selective with sex partners, alcohol ranks highest in terms of women being less likely to use a condom. The women's stories revealed that alcohol placed them as much at risk as did cocaine. Many women combined alcohol and cocaine use, further magnifying their risk. One of the women captured the link between alcohol and cocaine use as follows:

There ain't no way I can smoke rocks all day long. I don't have the money for one thing. Rock is hard on your body. It makes my heart race, like I don't know if it's gonna make it . . . Booze helps me get my heartbeat go slower . . . The booze is good for when you are coming down, too. It makes me still want a rock, but you'd be thinking about it, getting drunk, and not getting off your behind . . . But I'll need another rock sooner or later. I'd be walking around all drunk and stuff, and I'd be needing a rock badly . . . I'd do whatever they tell me to as long as I can get a hit . . . Half the time I don't even (\*\*\*\*\*) remember what happened. I guess that's good for me . . . I'm afraid by me smoking rock and getting drunk, I'd be getting the package [becoming HIV infected].

Using marijuana and heroin seems to have less impact on the women's sexual behavior, although a substantial number of women

reported that the use of these drugs elevated their HIV risk taking. The women's explanations indicate that the link between drug use and sex is more complex than often is assumed.

To explore this topic further, the women in Project FAST were asked to specify whether sex was more pleasant if they used a certain drug and if they disliked having sex with a partner who used alcohol, marijuana, heroin, or cocaine. Their responses are summarized in table 3.

**TABLE 3 Sex and Drugs: Women's Pleasure and Partner's Drug Use (Percentage) (N=259)**

| Drug      | Sex is more pleasant after the use of drug | Dislike sex after the sex partner has been using drug |
|-----------|--|---|
| Alcohol   | 83.3                                       | 51.1  |
| Marijuana | 86.4                                       | 20.4  |
| Heroin    | 59.2                                       | 38.5  |
| Cocaine   | 40.4                                       | 42.8  |

A majority of the women perceived that all four substances made their sexual experience more pleasant. More than four-fifths stated that marijuana enhanced their sexual experiences. In addition, only one-fifth of the women objected to having sex with a partner who had been smoking marijuana. The reasons for this have been described earlier and to a large extent overlap with those mentioned for alcohol. Approximately four-fifths of the women in this study described sex after having alcohol as more pleasant. They described feeling less inhibited, less worried about their physical appearance and their performance, and more physically sensitive. A combination of psychological and physiological factors contributed to the perception that alcohol enhanced the women's sexual experiences. On the other hand, one-half of the women indicated that they disliked having sex with a sex partner who had been drinking alcohol. The most commonly mentioned reasons for this were the offensive smell of

alcohol on their partners' breath (especially if the women themselves had not been drinking), the tendency of many men to become overly aggressive and to want to demonstrate their power, and the inability of many men to perform sexually after they had been drinking, which often resulted in their blaming the women for this failure.

Almost three-fifths of the women in this study perceived sex as more pleasant after they had been using heroin, but almost two-fifths of the women preferred not having sex at all with a partner who had been using heroin. Heroin use made most women want to relax, and heroin's psychopharmacological effect caused men to have difficulty performing.

The women's responses regarding cocaine use and sex contradict public beliefs about cocaine as an aphrodisiac. Three-fifths of the women in this study did not view cocaine as a substance that improved their sexual experiences. In addition, two-fifths of them disliked having sex with a partner who had been using cocaine. The women frequently described sex after cocaine use as unpleasant because they felt nervous, anxious, and jittery. Cocaine also reduced voluntary control over their muscles. The following excerpt from one of the interviews shows the women's reasons in more detail:

Cocaine is a funny drug. It messes with you, and sometimes you don't even know it does. I used to be shooting up speedballs [combination of heroin and cocaine] all the time. It's the perfect combination, with the heroin bringing you down and the cocaine getting you up . . . A few times, the heroin was so bad around here, I'd shoot up cocaine by itself. That's something . . . It makes me tingle, and I can feel every nerve in my body. I start sweating, and I almost can see it come out of my skin . . . But I don't care for it too much. It makes me nervous and scared. I hear all kind of sounds and don't know if that's real or some kind of sound in my head . . . The next day, I feel like I just ran a marathon . . . The crack is a little better, but it's cocaine you know . . . It makes me bite my tongue, I pick my face, and it makes me feel like I have bad cramps in my arms, my legs, and everywhere.

Several women complained about vaginal dryness after having used cocaine, which caused irritation during vaginal intercourse with a partner who was unwilling to use a lubricant.

The link between drug use and sex also differed by the social setting where the sexual encounter took place. For example, women who smoked crack in a setting where other users were getting high, crack was being sold, and sex was tolerated often ended up having sex with men who also used crack. In addition, the sex often took place in the crack use setting, sometimes visible to others. On the other hand, women who used crack only in the company of one or more friends, often reported that sexual activity that occurred was limited to those persons present, who typically all knew each other and who often had worked out “unwritten rules” about acceptable behaviors. Similarly, female IDUs who supported their habit by working as street prostitutes often reported that they would propose condom use with a paying partner but not with their steady partner. Similar findings have been reported elsewhere in the literature (Kane 1990; Sobo 1995; Sterk 1990).

The actual circumstances of sex under the influence differ by the drug used. However, other factors influencing the dynamic relationship between drug use and sexual activity should not be ignored. One of the main factors for sex under the influence, but more importantly for the women’s lives in general, is the women’s negotiation skills.

Social psychologists have conducted most of the research that focuses on understanding behaviors and the potential for behavioral change. Much of the intervention work in the area of HIV is dominated by sociopsychological theoretical perspectives. These perspectives tend to emphasize attitudes, beliefs, self-esteem, and self-efficacy. Other researchers stress the relevance of community norms. One of the weaknesses of these perspectives is that the social context is often ignored. For example, an IDU who gets high with other users who share their drugs and paraphernalia may intend to inject safely. However, this person’s good intention may be defeated by “negative” or unsuccessful negotiations. The social context in which behaviors occur may be a better predictor of safe behavior than individual attributes or community norms.

In the case of women, negotiation can be discussed only when gender role expectations and power differences between men and women are taken into consideration. Women are expected to be caring, nurturing individuals who need men to survive. Consequently, women often are allocated less power and control in mixed-gender interactions. Many of the women in Project FAST self-identified as heterosexual and often made references to role expectations and

power differences. Many women described their fear of getting AIDS and knew that they could protect themselves from becoming infected with HIV by using condoms. They had every intention of using a condom every time they had sex. In actuality, however, many women engaged in unprotected sex because they feared the negative reactions of their male partners. In situations involving a steady partner, they feared being accused of not trusting him or not being monogamous themselves, losing the relationship, or being subjected to verbal or physical abuse. When dealing with casual partners, the fear of violence and abuse was at the forefront, and in the case of paid encounters, the women often mentioned not having the luxury to chance losing their income. Sexual negotiations are inherently complex and become more complicated when sex occurs in the context of drug use.

### **Social Networks: Drug Buddies, Sex Partners, and Anybody Else**

Recent studies using a social network perspective have shown that such an approach provides a useful framework for predicting HIV transmission (Auerbach et al. 1984; Friedman 1995; Klov Dahl 1985; Latkin et al. 1995; Trotter et al. 1995). Findings from these and other studies reveal that social networks—the structure of social relationships—provide opportunities as well as constraints for their members. For example, although the social network of an IDU provides access to drugs and to an environment in which injection drug use is acceptable, that same network may put pressure on the user to share drugs and injection paraphernalia (Neagius et al. 1994). The women in this study confirmed the results of other studies, that the social networks affecting their lives varied by a number of factors. For example, women who were central in a drug network received more emotional and material support from other network members than women who were at the periphery of the network. One of the women in a peripheral role shared the following:

It makes me jealous. Okay, I'm part of the group, and they let me get high with them and stuff, but I'm not really part of it. I don't know how it happened . . . No, it's not a woman thing. There are some ladies who get it all. I mean, people bend over backwards for them. They need something, they'll get it . . . Sometimes when things are slow, I sneak into one of the other get-off houses [places where people use drugs together, similar to shooting galleries]. They can't do that. It would (\*\*\*\*\*) people off. I guess that's the good part of not being in the group all the

way . . . I try to rationalize it, but it does bother me that they don't look out for me like they do for some other folks who hang out here . . . They watched me being ripped off by this man right in front of them.

Other women in peripheral positions shared similar experiences. Several women complained that the members of their social network felt less obligated to protect them from others, especially from men seeking free sex. At the same time, they all described certain advantages of not being central in a network, with the perceived level of freedom as the most frequently listed advantage.

The impact of the women's drug network also differed by the length of time that the members had known each other. While some women mentioned they had been using drugs for several years with basically the same group of people, others often changed their network each time they had a new boyfriend. One woman described how she had moved from network to network over the past 6 months:

I don't know who my friends are anymore. I used to be part of something. Not like close friends, but I knew where I could go if I needed money, dope, or a place to crash. I blew it. See, part of my problem is that I want an old man [steady partner] bad, I mean bad. I'm almost forty, and it's the only thing I want out of life. Have my own old man . . . I am a sucker for any guy who tells me what I wanna hear. I tell a guy that I love him and want to be with him for the rest of my life before I even know where he came from . . . Over the last six months, I had five different guys move in with me. Every time, I'd hang out with him and his friends, had his friends crash at my place, and turn away from my own friends. I'd stop buying from my own guy, don't share any of my stuff, and let the guy handle it [drug purchasing] for me. They are (\*\*\*\*\*) with me . . . What it comes down to is me not having what'd you call that [network] of my own.

The drug networks of many women largely reflected their partner's affiliations. Many women not only moved away from their drug networks but also distanced themselves from their social networks. It appears that the more established a woman is in her drug network, the more likely she is to be respected by the other network members and the more control she seems to have over her life. For example, few of the women who were central, long-term members of a drug

network felt forced to use or share their drugs or to have sex with another network member.

A number of women became, as one woman called them, “dead ends.” They had moved through many different networks, in all or most of which they held peripheral positions. As their drug buddies became alienated because the women were unable to support their own drug habit and as their sex partners distanced themselves because they had no respect left for the women, they become increasingly isolated.

Most women in Project FAST reported a significant overlap between their drug and sex networks. If the women were involved in a steady relationship with a man, both partners most likely belonged to the same network, often his original group of acquaintances and friends. Among those women who exchanged sex for drugs, two patterns were identified. IDUs seldom reported an overlap between their drug buddies and sex partners. This division between drug and sex networks was largely related to the fact that the women typically exchanged sex for money, which in turn was used for drugs. While the drug-sex connection was weak with paying sex partners, this connection was common with nonpaying partners, specifically with the women’s steady partners. Women who exchanged sex for crack, on the other hand, frequently reported that they had sex with individuals from the same networks as their drug networks. This overlap in networks resulted in collective as opposed to individual behavior patterns:

You have to see it this way. We hang out at the house [crack house], and the guys know that I’m one of the girls who’ll be running out of money . . . They know I need to freak [engage in sexual activity] to geek [get high on crack] . . . I’ll end up giving one of the guys a job or performing with one of the other girls . . . They know I need the rock, and they tell me what to do. It doesn’t matter what I want . . .

Many women indicated that most of their behavior was an outcome of group processes. Their stories revealed that being peripheral network members, in both the drug and sex networks, resulted in limited control over their actions.

The women were asked not only about drug and sex networks but also about other social contacts, individuals who were neither drug

nor sex contacts. The most common social contacts involved relatives, especially mothers, sisters, the women's children, and to a lesser extent, the women's case managers. Typically, the more social contacts a woman listed, the greater her resources. Whereas their drug contacts supported their drug use and their sex contacts were part of their sexual activity, their social contacts frequently provided support when the women needed a place to stay, someone to take of them or their children, or someone who was willing to listen to them.

The women's drug and sex networks also affected their HIV risk. By moving from one network to another, the women served as transmission bridges between networks. In addition, the group in which they participated most frequently set the norms for acceptable HIV risk and protective behaviors. Furthermore, the women's HIV risk varied depending on the presence or absence of HIV infection among their network members. One woman described how she had engaged in high-risk behaviors. She was tested for HIV within the past 3 months and again tested negative, after two previous tests over the past 18 months:

I don't know about the virus. You know, I think they are telling us that we're gonna die of it, but what they really want is for us to stop shooting up and smoking rock . . . Nine out of ten times I shoot up with a dirty needle. I always clean it with water, but cleaning with bleach scares me. I think it makes people sick, bleach is not healthy, you know? . . . When the heroin gets like milk powder [low quality], I may smoke some rocks. I love going to the parties where everyone is (\*\*\*\*) around and high as hell . . . Honey, I don't use rubbers. I once got a rash from a rubber; it's not good for a woman . . . I know you don't agree, but let me tell you, I ain't doing the right things, but I ain't infected either.

On the other end of the continuum, a woman who almost always engaged in protective behaviors, but who recently tested HIV positive, said:

I always take care of myself. I get myself checked out, I always use a condom . . . I know so much about being safe, I could be one of the AIDS street team educators . . . One time, only one time, did I have sex without a condom . . . We started out using one, but he started acting up . . . I know that is the only time I could have gotten the virus.

## CONCLUSIONS

Although epidemiological data provide important information on drug use, sexual behavior, and HIV trends, ethnographic data complement the knowledge and understanding about HIV.

Ethnographic data not only place epidemiological data in context but also provide explanations and theoretical frameworks of how and why trends occur. The findings presented in this chapter show the value of integrating epidemiological, ethnographic, and social network approaches. The ethnographic data presented reveal the complex link between drug use and sexual activity, the impact of the type of drug used, the social settings of drug use and sexual activity, and the economic forces influencing the ways in which the women supported their habit. Additional insight was provided by exploring the women's social networks, including their drug partners, sex partners, and social contacts with whom they do not either use drugs or have sex. These ethnographic findings provide the context for epidemiological trend data, the most recent of which show increasing HIV infection rates among women (Centers for Disease Control and Prevention 1998).

Analysis of the ethnographic data reveals the gender specificity of HIV risk among women. The women's stories show how gender is closely linked to power: power in their interactions with men and power in their interactions with their network members. The women's behaviors may be "captured" in numbers; however, numerical counts do not acknowledge the context in which HIV risk behaviors occur. For researchers and public health professionals, this means that despite the desire to narrowly focus educational messages, prevention and intervention efforts need to address all components of the women's lives in an order that is prioritized by the women themselves. Whereas some women may be interested primarily in developing parenting skills, others may want to focus on developing healthy relationships, and others may say that stopping drug use is their top priority. Currently, policy decisions and program development are based largely on epidemiological indicators. Policy formulation and program development would benefit greatly from careful consideration of information obtained through ethnographic exploration of the context of HIV risk and drug use.

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# **Chapter 6. Researching Risk: Prevention Research on Substance Abuse, Sexual Behavior, and HIV/AIDS in Asia and Australia**

*Lenore Manderson*

## **ABSTRACT**

This chapter addresses two separate but related points: (1) the merits of multidisciplinary research to ensure valid and useful study results for the development of health interventions in the areas of substance abuse, sexual behavior, and HIV/AIDS and (2) the importance of research collaboration with communities to identify risk behaviors and to develop, deliver, and monitor interventions that are acceptable and sustainable for particular groups. Included is a discussion of research conducted by Australian investigators in Asia and Australia with Indigenous Australians, which involves close collaboration across public health disciplines and among institutions and reflects a commitment to community involvement and linking anthropological research to program needs. The mechanisms used to establish community support and maintain community involvement through consultations and the operation of reference groups are described, and the importance of this approach in defining research questions of relevance to communities is discussed. Attention is also given to the importance of the macroenvironment—the politics and economics of infection—as the context that must be recognized as influencing sexual practices and drug use and affecting the success of interventions.

**Key words:** Asia, Australia, Indigenous populations, sex research, rapid ethnographic assessment, research ethics

## **INTRODUCTION**

Since the behavioral factors implicated in the transmission of the human immunodeficiency virus (HIV) were first identified, there has been a dramatic expansion of the literature on the social aspects of HIV infection, the cultural and political contexts of transmission and

prevention, the development and sustainability of interventions, and issues associated with caring for people with HIV and acquired immunodeficiency syndrome (AIDS).

As is now well documented, much of the research conducted through the 1980s concentrated on at-risk populations in industrialized countries. Methodologically, these studies were often flawed in their design, sampling, choice of methods, and reliability and validity. Many were knowledge, attitudes, and practices (KAP) surveys with opportunistic samples, which generated information of little value to either understanding the complexity of the disease and the social responses to it or developing practical and effective responses.<sup>1</sup> However, these studies drew attention to the extent to which HIV infection is socially and culturally embedded and the need for this to be taken into account in responses to the epidemic. As a result, the public health community has shown an unparalleled awareness of the importance of social science input in developing strategies for the prevention and management of HIV/AIDS (King 1997). This has encouraged increasing interdisciplinary debate and research, and in this context, researchers have become cognizant of the complexity of issues related to HIV and the need to approach these creatively.

This chapter addresses some of the methodological difficulties associated with substance abuse and sexual research related to the prevention of HIV/AIDS and relates these difficulties to various projects undertaken in Australia and Asia. These are anthropological projects conducted from a public health perspective, some with the objective of generating baseline data and describing the social and cultural context of HIV transmission and others whose data relate more specifically to the development, delivery, and assessment of interventions.

## **SOCIAL RESEARCH AND THE QUESTION OF METHODS**

Decision making concerning HIV policy and prevention strategies and the tasks of developing, implementing, monitoring, and evaluating related programs require reliable information with respect to the distribution of the disease and risk factors for transmission. The argument for anthropological research related to injection drug use, sexual practices, and HIV infection is not therefore an exclusive one; it also recognizes the importance of the continuing collection and analysis of other relevant epidemiologic and demographic data.

The collaboration of social scientists and other researchers (clinical and epidemiological) presumes a two-way flow: Such collaboration (1) facilitates the integration of knowledge from the social sciences, the humanities, and the medical sciences and (2) enables anthropological research to be directed and informed by epidemiological and clinical understandings in ways that might be highly significant in terms of research direction and outcome. This is not necessarily an argument for interdisciplinary research, since timeframes, sampling procedures, and research populations vary. It is, however, an argument for continuing dialog among disciplines to focus and maximize research resources (individuals and dollars).

Epidemiological and social surveys are expensive because of the complexity of their organization and execution. In addition, their comprehensiveness of coverage is offset by their limitations in uncovering the underlying motivations for and meanings of specific behavior and activities and the ways in which these interact with the wider social and cultural environment. In this public health context, anthropology's strength has been to offer the corrective to such superficiality. Both conventional anthropology and rapid-assessment procedures supplement survey data, offering theoretical approaches to interpret it (Manderson 1997; Manderson and Aaby 1992; Scrimshaw and Gleason 1992; Scrimshaw and Hurtado 1987; Singer 1991).

This chapter is primarily concerned with method. Anthropology offers to public health, including HIV, a methodology to explore the social, cultural, economic, and political contexts of illness; explore vulnerabilities to infection; and identify behaviors implicated in transmission and feasible for intervention. The value of rapid-assessment procedures is not that they replace conventional ethnographic research. Both approaches enable the collection of qualitative data to complement survey data, but extended research is essential for a nuanced understanding of the issues in question. Rapid assessment has its place in identifying research questions to be pursued through other methods, helping develop and refine interventions, and identifying indicators appropriate for the monitoring and evaluation of programs.

KAP surveys, used early in the HIV/AIDS epidemic to identify social and behavioral aspects of infection, relied on questionnaires to document knowledge of infection and prevention and to test the acceptability of and adherence to prevention practices. This

methodological approach had immediate advantages, given the familiarity of epidemiologists and other public health researchers with questionnaires as instruments to elicit demographic and behavioral data, despite the limitations of this method in collecting personal and sensitive data (as well documented for family planning and population research; see, for example, Bleek 1987; Stone and Campbell 1984; Vlassoff and Vlassoff 1978).

Depending on the study design and sampling procedures, KAP surveys provide quantifiable and generalizable data on knowledge and attitudes. The instruments are not flexible enough, however, either to uncover the basis of attitudes or to validate reported behaviors and practices. Thus, KAP surveys provide information on normative, ideal, or typical behavior, but are weak in describing variations in behavior and the gaps that exist between stated and actual practices. Indeed, both surveys and more flexible interviews are problematic as means of collecting such information (Dean and Whyte 1969; Kirk and Miller 1986), especially where the subject matter is sensitive or the practices illegal, where the respondent is asked to generalize, or where "courtesy" bias results in normative replies. A variety of inaccuracies also arise in relation to self-reports and recall. Sexual practices—abortion, frequency of intercourse and contraception, numbers and changes of partners, and practices related to alcohol and other drug use—are rarely discussed openly and are vulnerable to interviewer/interviewee variables and the context of the interview. Such research also presents difficulties, for example, with regard to definitions of acts and frequency of behavior, leading to either underreporting or overreporting. These difficulties are true for injection drug use as well as for sexual practices: Respondents may be wary of speaking openly about use of illicit drugs in surveys, and in face-to-face interviews they may be influenced by issues such as age, gender, race, and class.

Once a relationship between interviewer and interviewee is established, extended interviews enable more complex information to be collected where observation is usually not possible, as occurs for various issues relevant to HIV/AIDS transmission (compare Bolton 1992; Henriksson and Mansson 1995; Vincke and Bolton 1995). Interviews conducted in the context of ethnographic research or ongoing community intervention programs (Stevens et al. 1998) have a better chance of internal validity, since the researcher is more likely to know the interviewees, to be able to interpret interview responses in context, and to cross-check information through repeat interviews.

This more intensive approach has led to more sophisticated inquiry, for example, through the use of diaries, postdiary interviews and observations (Coxon 1988; Coxon and Coxon 1995), and explorations of how social networks operate in terms of what Friedman and colleagues (1997) refer to as “person-to-person sexual and syringe-mediated interactions.”

## ON EPISTEMOLOGY AND DEFINITION

Along with the growing awareness of the limitations of surveys for collecting social, cultural, and behavioral data has come increased incorporation of qualitative methods in health research and a particular emphasis on combining qualitative and quantitative methods to allow for triangulation of data (Brannen 1995; Breitmayer et al. 1993). Much public health research, including studies on HIV/AIDS and injection drug use, incorporates anthropological approaches using records and other documentation, observational data, a variety of interviewing techniques such as indepth and life-history interviews, and focus groups (Baum 1995). However, the quality of this research is variable where qualitative methods are incorporated without an understanding of the epistemology and theory of anthropology that facilitates data interpretation.

Anthropological research is by its nature inductive, designed to discover the unexpected. Anthropological methods are sometimes difficult to describe in a way that fits with epidemiological and other biomedical research models. This has led to greater explicitness of methods in writings by anthropologists to clarify such issues for medical and other social scientists. At the same time, the form of reporting remains distinctive. Arguably, the finest and most innovative ethnographic research on HIV/AIDS and drug use is still published in monograph form rather than in shorter articles in “scientific” journals (Bourgois 1996; Sobo 1995; Waterston 1993), thereby ensuring anthropological readership but perhaps reducing access by public health professionals.

One of the challenges facing researchers working on issues related to drugs and sex, gender, and sexuality has been the negotiation of territory among the various disciplines and professions involved in the field. Anthropology and other social sciences on the one hand, and biology and the clinical sciences on the other, have very different starting points and endpoints, derived from and resulting in

epistemological and paradigmatic gaps. However, research conducted in the context of the HIV epidemic has been unlike research conducted in other areas, where there is clear demarcation of the contributions of different disciplines and where personal investment is muted or irrelevant. In HIV/AIDS research, activist, community, and research perspectives overlap for individuals; the personal and professional “stakes” at times overlap; and subjective interpretations of research findings remain in the foreground (Kulick and Willson 1995). Consequently, HIV/AIDS research is often a political minefield, and the philosophical, moral, and political stances of investigators influence the research agenda and the reception of findings (Manderson 1994).

Elaboration on these points may clarify the role of anthropology in the context of HIV research. The positions of social construction theory and biology have been treated as mutually exclusive, but this is a crude characterization and misrepresents both perspectives.<sup>2</sup> Anthropology and sociology in general take as a theoretical starting point the idea that sexuality is culturally constructed.

Anthropologists do not discount the biological basis of sex; rather, the issue is the way in which particular biological acts are understood and institutionalized in given social and cultural contexts. Gender and age are similarly fluid concepts that take on very different meanings depending on social formation, belief systems, and so on. For example, notions of infancy, childhood, adolescence, middle age, and old age vary in different societies, according to subsistence base, level of industrialization, gender relations, and so on. In some cases, the lines between childhood and adulthood are blurred, with roles defined by physical capability rather than chronology; in other cases, role transitions are marked by major ritual observation. Similarly, in some cases, adulthood and maturity are reflected by the adoption of social, political, and economic roles rather than chronology.

Likewise, gender is not derived uncontroversially by sex at birth and may not be as neatly bifurcated as it is in Western societies (compare Herdt 1996; Jackson 1997). Cultural elaborations of gender derive from but are not confined to biological status. Similarly, sexuality—the subject of much HIV research—is not *given* in nature (i.e., sexuality as distinguished from mating behavior). The literature related to the construction of sexuality, to about 1990, has been summarized by Vance (1991), who argues that sexuality and sexual relationships are determined (structured) by values and norms that

differ by time and place, convention, ethics, institutions, culture, class, and gender. Given this, a fundamental question in HIV research is the portability of the concept of sexuality. How is this operationalized in various social and cultural contexts? What do we research under this rubric? The presumption is that sexuality has ontological status (i.e., it exists). However, this attribution, outside of specific discursive frameworks, collapses in the face of Indigenous accounts of sex and sexual congress. For example, childbirth, lineage, inheritance, and so on are not conventionally incorporated within contemporary Western notions of sexuality but elsewhere may be constitutive of sexual status and identity, serving both to direct sexual expression and define social being and personhood (Willis 1997).

To illustrate these points briefly, in cultural contexts where male initiation involves handling the penis—either sexually (e.g., through fellatio or sodomy; see Herdt 1993, 1994) or in terms of ritual or ceremonial acts—the penis signifies acts of sociality, personhood, and adulthood but not necessarily sexuality (Willis 1997). Furthermore, if sexuality infers essential links with personhood, following Western postulates, then the absence of notions of person/self, origin, and corporate identity suggests that different meanings also accrue to sexual behavior. If the notion of an identity is derived not from sexuality but rather from nation, tribal affiliation, race, or place, then the links that exist between sexual behavior, corporeality, and sociality take on quite different meanings. At the same time, sexuality is problematic where the community is regarded conceptually as predetermining the individual and the individual exists conceptually only in terms of his or her relationship to the community. These alternative understandings of the body, sexuality, and personhood would appear to influence perceptions of risk and decisions to seek diagnosis and treatment for sexually transmissible disease (Mulvey and Manderson 1995). In these examples, the notion of an individuated subject of sexuality, that is, a “sexual self,” makes little sense. However, such notions are fluid and evolving, and Clark’s work (1997) on sexual exchange, men’s sexual behavior, and men’s perceptions of women in developing Papua New Guinea highlight the differences of corporeality and sexuality and the implications of this for HIV transmission and prevention.

Female sexuality is tightly linked to reproduction in most places, even where continuing exposure to different perceptions (e.g., through the media and interaction with other cultures) might challenge this (Jennaway 1996; Whittaker 1995). Hence, notions of the universality

of sexuality, sexual orientation, and gender identities are fluid and contested.

In her documentation of young women's negotiations of their sexual and personal identities in Lombok, Indonesia, where sexual activity outside of marriage is condemned, Bennett (1998) provides an example of the problematic nature of maidenhood and sexuality for women. Here, as elsewhere in Southeast Asia, understandings of gender, sex, reproduction, and the family are counterpositioned against Western ideas of sexuality and personhood that are transmitted locally via globalization, the rapid expansion of tourism, and a consumer economy. For young Sasak women in Lombok, the capital city offers a cosmopolitan environment that provides personal and economic freedom that contrasts greatly with village life; this changed environment encourages changes in women's ideas about sex, courtship, love, marriage, and motherhood and, indeed, about sexuality.

This is also the case in Bali, where Jennaway (1996) examined the social context and risk factors associated with the transmission of HIV. In Thailand (Lyttleton 1994; Manderson 1995) and to a lesser extent the Philippines (e.g., Law 1997), sex work and injection drug use (see especially Stimson 1997; Wodak et al. 1993) are major risks for transmission of HIV infection. In contrast, female chastity in Bali remains highly valued, female sex workers are less common and are stereotyped as outsiders ("Javanese"), and intercultural liaisons are primarily romantic interludes—lasting days or weeks—between local men and female tourists. As a result, however, local women are not immune from the risk of sexually transmitted infections. Maternity is highly prized. Women may establish sexual relationships at a relatively young age, before marriage, and even—at the cost of being a minor wife—to conceive. Men's sexuality is loosely monitored, and women are reluctant to present at health services with reproductive tract infections (see also Hull et al. 1996). Although liaisons with European women are arguably a low-risk activity, men are not immune to HIV infection. Research by both Jennaway (1996) and Bennett (1998) illustrate the problems of focusing HIV interventions on target groups that are, on the basis of their behavior, at greatest risk of infection while ignoring the less obvious risks facing all sexually active people.

## THE PROBLEM OF RISK

There has been considerable criticism of the use of risk as a means of identifying areas for baseline research or for interventions for HIV/AIDS or other diseases (Patton 1990), in part because of the reactive nature of interventions, with new public health categories emerging as infection has spread. The HIV epidemic in Thailand, for example, has been represented chronologically as an infection that has moved progressively from foreign homosexual men to local "homosexuals," to injection drug users (IDUs) to "prostitutes," to the general male population, to housewives, then to unborn children (Lyttleton 1994; Songwathana 1998), with little reflection on the construction of apparently discrete categories or on the logic that assigns risk to populations retrospectively (Kane and Mason 1992). The identification of risk groups, which still dominates public health thinking in the region, has failed to be sufficiently elastic to account for different sexual cultures and for the structural factors that have led to increasing pockets of infection and HIV's widening distribution in poor countries and populations (Farmer 1992, 1995; Law 1997; Porter 1997; Savage 1996). This political economy of HIV has been acknowledged, however, by those designing and supporting interventions, as reflected in the interest of the Joint United Nations Programme on HIV/AIDS and other World Health Organization agencies in using rapid-assessment protocols to describe the local contexts of infection, transmission, and intervention (Abaogye-Kwarteng et al. 1997).

Anthropological research has drawn attention not only to variations in clinical, epidemiological, and lay understandings of disease transmission and treatment but also to prevention and risk, that is, the translation of epidemiologic and public health categories into popular discourse and programs (e.g., Janes et al. 1986). In HIV-related research, epidemiological risk has resulted in the identification of particular marginal groups such as gay men, prostitutes, and IDUs, conventionally reflecting the known burden of infection without acknowledging the problematic, fluid, and overlapping nature of these groups. Public health focus on these populations as "target groups" has resulted in the greater stigmatization of members of certain communities, as if all were infected or were vectors of infection (hence, also the allocation of blame; see Songwathana 1998). At the same time, this targeted approach to interventions ignores the complexity of sexual and social networks, making this, in terms of a disease control strategy, dangerous (Murray and Payne 1989).

Indeed, the marginalization of communities associated with HIV/AIDS has made it less likely that individuals would identify personally with such groups.

Population definition is extremely difficult, and populations at risk of HIV infection have tended to be identified through social networks of community service agencies (e.g., health/medical clinics), social organizations, local media, and so on (Fullilove et al. 1990; Valdiserri et al. 1989). However, as suggested above, such populations are not fixed categories (de Zalduondo 1991; Lyttleton 1994; Schoepf 1992, 1995). Many women (e.g., mothers, housewives, students, nurses, etc.) may sell sex among a range of activities, and sex work may be a full-time, part-time, or casual occupation for varied lengths of time. Perhaps only a small proportion of women and men sell sex in identifiable neighborhoods, particularly where prostitution is an offense. Similarly, IDUs are not visible or readily identifiable, and the challenge in developing health interventions relates precisely to outreach across structural boundaries such as class and age.

Other categories of “target populations” and “risk groups” are similarly problematic. As already suggested, the collapse of sexual orientation, behavior, and identity to define “homosexual,” “heterosexual,” and “bisexual” provides one example of the danger of using simple categories that are unable to accommodate variation in identity and practice across cultures and exclude large numbers of people who engage in certain behaviors but are unconnected and do not identify with established sexual communities—for example, men who have sex with men (see, e.g., Dowsett and Connell 1993). As Jackson (1997) describes, in Thailand men do not regard men who have sex with men, either as regular lovers or as casual partners, as impinging on their sexual/biological identity (male) or their gender/sociocultural identity (maleness, masculinity); moreover, this does not produce a category that accounts for sexual identity (see also Parker 1987, 1991 [Brazil]; Prieur 1998 [Mexico]).

Similarly, Brough (1994) has criticized the use of “youth” as a risk category, not simply because of different age boundaries but also because of the stereotyping of young people as “risk takers” and the associated suppositions about their sexual and other behavior (e.g., substance abuse). This ignores variables such as class, education, employment, sexual history, marital status, maternity history, and so on (see also Frankenberg 1992; Kane and Mason 1992). Again, although we know far less about drug-using populations (Singer

1991; Stevens et al. 1998), illicit drug users may either belong to relatively distinct groups or be isolated from any particular “community,” with little in common with other users.

The alternative approach to risk, as advocated by scholars such as ten Brummelhuis and Herdt (1995) (see also contributions in Herdt and Lindenbaum 1992), is the exploration of sexual culture, which in IDU-related research, has been expanded to explore the cultures of drug use (Kane and Mason 1992; Larson 1996; Larson et al. 1997). This approach explores the social context of behaviors and practices that might result in risk of infection and lay understandings of risk, thus incorporating the social, economic, and other dynamics resulting in or coincident with risk-related behaviors. Only on this basis, such authors have argued, is it possible to develop acceptable and sustainable interventions. This approach still focuses on behavior, which is very much influenced by less pliable structural factors.

## WHY CONDUCT ETHNOGRAPHY?

The lengthy time involved in conventional anthropological research has resulted in its limited support by public health practitioners. Instead, there has been considerable interest in the use of rapid-assessment methods to collect social and cultural data promptly (see below). Ethnographic research with the community involved illustrates the value of allowing research questions rather than notional time costs to drive the choice of method.

HIV/AIDS and other sexually transmitted diseases (STDs) and injection drug and other substance abuse are contentious areas for research because of issues of access to certain communities. However, they are also contentious because of problems related to the release of information about the prevalence of certain infections or behaviors. In Australia, this is frequently sensationalized in the popular press, resulting in shame accruing to identifiable communities but no changes in policy or programs.<sup>3</sup>

In response to the reluctance of Indigenous Australian communities to collaborate with researchers, the National Health and Medical Research Council (NHMRC) and the National Aboriginal Health Strategy developed clear guidelines on the conduct of research, emphasizing that any research must be designed with and for the community (Kelaher et al. 1998; Manderson et al. 1998). The focus is

on community control and involvement as well as the relevance and use of study findings. Guidelines specify the involvement of Indigenous people in defining the research questions and monitoring research processes (Australian National Health and Medical Research Council 1991). Other minority communities (e.g., sex workers, persons from non-English-speaking background communities, etc.) have not sought such strict formal guidelines. Nevertheless, community councils or coordinating bodies often exercise similar gatekeeping functions and require reference groups of individuals nominated by and representing community interests or seek other consultative mechanisms to be established prior to collaborating in research. This modus operandi does not preclude basic research but places responsibility on researchers to negotiate their roles with study populations and make transparent their aims and objectives. Permission to enter an Indigenous community prior to developing a research project, for example, is a negotiated privilege. Given this, conventional study approaches and rapid assessments are rarely feasible.

Three research projects with Indigenous Australians illustrate this. Willis' work (1997) with the Pitjantjatjara in central Australia focuses on men's understandings of health, the diagnosis and management of STDs, and ceremonial activities that have a high risk of transmission of sexually transmissible infections, including HIV. Access to information is largely restricted to initiated men. By definition, such information will not find its way into the public domain, and the specific behaviors will be addressed in risk-reduction activities developed by Pitjantjatjara people themselves. Willis' knowledge and ability to work with elders to develop relevant interventions were largely a result of his 10-year residency in the community as an employee of the community, his linguistic fluency, and his cultural competence. Similarly, Hammill's research (1999) on what she refers to as a "culture of chaos" has been built on interpersonal associations that extend beyond the relatively instrumental roles of researcher and research subject. Her work in an Indigenous rural community on issues related to alcohol and other drug abuse, violence, sexual behavior, and HIV risk has been contingent on her ability to establish and sustain extensive reciprocal relationships with the women and her willingness to contribute to community betterment in ways determined by these women. Hammill's relationship with the study community also has illustrated how kinship and personal (Indigenous) identity were only provisional entry cards and that

access to knowledge—the anthropologist's commodity—is always conditional on sustained reciprocity.

Work with urban Indigenous Australian IDUs further highlights the importance of community collaboration and control. Larson and colleagues (Eldridge 1997; Larson 1996; Larson and Currie 1995; Larson et al. 1997) worked over a 2-year period on issues relating to injection drug use among young people, a group that interacts little with non-Indigenous Australian drug users and is also isolated from other Indigenous people. Consultations with Indigenous people working in the fields of sexual and youth health commenced in mid-1994, when they were invited to identify an issue that they felt warranted intensive research. The 2 years of research were then conducted with the support and advice of a reference group and involved consultations with service providers and key community members and interviews with IDUs conducted by trained peers. In addition, a survey of alcohol and other substance use among Indigenous youth was conducted, using targeted sampling via the identification of potential participants through social networks (Larson et al. 1997) and asking the participants questions that were informed from the prior collaborative work. The outcomes reveal a very high proportion of young men and women who routinely use alcohol, cigarettes, and marijuana; the early onset of use of these drugs; the lower rate (about 10 percent) of youths who had experimented with and regularly used other drugs such as hallucinogens, amphetamines, and heroin; and the strong influence of friends' use on drug-related behavior.

These research projects have a pragmatic emphasis, but they—and much anthropological research on sex and drugs—highlight discrepancies related to access to communities and raise issues regarding the subject matter of the studies (e.g., for Willis 1997 and Hammill 1999, definitions of sexuality and the contexts of sex). The projects emphasize the relevance of gender, age, and kinship affiliation but also draw attention to the need to take into account the historical and structural inequalities and abuses that influence contemporary violence and despair among these populations.

Concentrated anthropological research is not always possible, however, and other mechanisms are necessary to ensure community access or control. In work conducted with both Indigenous and immigrant communities, the author and colleagues have made wide use of community consultation and reference groups, the former to

ensure good community knowledge of our intentions prior to the commencement of any research or data collection and to explore avenues for collaboration and assistance. Reference group members are often identified through community consultation, with the group serving as an ongoing mechanism to support the researchers, advise on the appropriateness of research methods and topics, assist in gaining or maintaining community access, and assist with the interpretation of research findings.

The community is not the only group with an investment in the products of research. Much public health and intervention-related research is commissioned, with the successful conduct of the research and the subsequent use of findings partly dependent on the involvement of the funding body. Formal input may identify program-related needs and identify key research questions, facilitate access to official information, and encourage the use of results in the development or improvement of policy, programs, or specific services. In addition, the involvement of agencies as well as study communities provides researchers with some insights into the political, cultural, financial, and other resource problems that might be faced in developing or maintaining interventions. Pike (1998) suggests that cultural barriers to developing appropriate and acceptable programs occur at governmental and nongovernmental organization (NGO) levels and within "target" communities, where people developing programs adopt moral stances unsympathetic toward those at high risk of infection (because of occupation, ethnicity, gender, age, and a range of other factors) and face structural and institutional barriers.<sup>4</sup>

## "RAPID" RESEARCH APPROACHES

Various rapid-assessment methods have been developed for HIV/AIDS, STDs, and injection drug use (Howard et al. 1998; Manderson 1997; Manderson and Aaby 1992; Rhodes et al. 1998; Stimson et al. 1998). These methods dispense with some of the conventions of ethnography while ensuring that information on cultural and social issues are collected, using primarily qualitative (and some quantitative) methods to gather data over a brief period. The approaches emphasize triangulation through the use of multiple methods and, often, the involvement of several researchers from different backgrounds. Advocates of rapid-assessment methods highlight the advantages of observations, key informant and

ethnographic interviews to explore human behavior, local perceptions of the research issues, and the social and cultural contexts of such behavior.

There is no single formula for rapid assessments, since research questions (and populations) must necessarily determine the choice and mix of methods. This is clearly the case for HIV-related research, not only because of different study populations and issues of transmission but also because of the different levels at which cultural information is relevant. The contextual assessment of social and cultural factors relating to HIV/AIDS (Larson and Manderson 1997), for instance, emphasizes broad cultural, social, political, and demographic factors that constitute the environment in which policies and programs are developed, delivered, and monitored. These are quite different from the issues relevant to designing interventions with particular populations (e.g., homeless youth; see Howard et al. 1998). The contextual assessment emphasizes community, NGO, and government consultation through meetings and interviews and the review of published data rather than the collection of population-based information or individually collected data. The Targeted Intervention Research framework developed by Helitzer-Allen and colleagues for HIV and other STDs (Helitzer-Allen and Allen 1994; Helitzer-Allen et al. 1996), on the other hand, is designed for the development of specific interventions with the needs of the commissioning agency in mind. This approach identifies five levels of analysis—individual, social network, organizational, community, and public policy—that allow the identification of behavioral, structural, and administrative factors influencing possible transmission of infection and potentials for intervention. The aim is to discriminate between individual and population factors and those affecting the development of policy and delivery of services that can be addressed programmatically, and so in a rapid assessment ensure that information collected is appropriate, targeted, and useful.

Rapid assessment also provides a means by which anthropology can be involved in monitoring and evaluation. The need to document processes, identify and resolve problems, and establish the effectiveness of approaches from the point of view of various actors calls for a pragmatic and flexible research approach, which anthropology offers; there is little merit in interventions that are tested only in terms of limited outcome indicators (e.g., knowledge of HIV infection, number of new cases of AIDS, etc.). Testing and evaluating information, education, and communication (IEC)

material is a case in point, where social and cultural information must be collected to enable its development but where its acceptance and impact requires ongoing evaluation. IEC programs should be culturally acceptable and understandable, should fit with local ideas of illness and disease, and should take into account the availability of and access to services and local sensitivities regarding sexuality, disease, illicit drug use, and so on. Structural factors such as class and gender relations operate as barriers to the accessibility, affordability, and availability of services and affect policy, programs, and services as much as do knowledge of and attitudes about HIV, preventive behavior, and perceptions of risk. Ongoing information is critical for programs to work. Hence, anthropologists have roles as agency representatives as well as academics to monitor and respond to changes in the HIV epidemic.

## CONCLUSION

Anthropology is a serendipitous profession, allowing its practitioners to move across fields on an opportunistic basis, working at various levels of focus and inquiry as dictated by the questions of the moment and individual imaginations. To date, anthropology's involvement in HIV/AIDS research has been very much determined by the established epidemiology of infection, that is, research that has a population focus that reflects country prevalence and areas of inquiry that reflect the current public health paradigm. At the same time, anthropologists have resisted the notion of acting as the cultural interpreters of health interventions by providing the technical vocabularies, models, and social grammars that might best enhance epidemiological research or affect public health interventions. Even so, the notion of the cultural context of risk retains a focus on the individual.

This chapter proposes that anthropology offers a wider lens through which to view the practical and urgent issues of HIV prevention. The methodological approaches adopted in ongoing research with respect to drug use and sexual behavior draw attention to the importance of negotiating the relationship between researcher and researched communities on issues of high sensitivity and the importance of anthropological involvement in wider efforts, scholarly and governmental, in reducing HIV/AIDS infection. The practicalities of infection that tie prevention to needle exchange and condom use, as well as the political, economic, and social contexts of transmission,

require attention, while taking into account global and local inequalities, poverty and injustice, and the specifics of sexual behavior and drug use.

## NOTES

1. For example, in the first decade of AIDS research, some 2,000 studies were conducted on the acceptability and use of condoms among heterosexual populations in industrialized settings. Virtually all of these studies concluded that most people do not like condoms yet will use them sometimes and that use is situationally determined. The justification for such a large volume of research on this question, and its impact on HIV prevention, is debatable (Manderson et al. 1997).
2. Some fierce communications appeared in the *Journal of Sex Research* in the late 1980s from “social constructionist” and psychobiological perspectives, which although now dated, are routinely reenacted in interdisciplinary meetings at which the perspectives of both tend to be overstated and misunderstood.
3. Researchers are faced with some dilemmas when permission to publish is withheld by the community and research efforts are consequently perceived as “wasted” in terms of conventional grants-driven methods of assessing output. However, communities are correct in pointing out that health problems are well known, yet there remains little political or social policy action.
4. See Whittaker (1995) on ethnicity and Williams and colleagues (1996) on institutional impediments.

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# **Chapter 7. Neighborhood Violence in New York City and Indigenous Attempts To Contain It: The Mediating Role of the Third Crown of the Latin Kings**

*Ric Curtis and Ansley Hamid*

## **ABSTRACT**

In the study described in this chapter, ethnographic methods and techniques were used to examine, frame, and contextualize the resurgence of grassroots political mobilizations among New York City youths in the 1990s, in particular, the Latin Kings and Queens. Labeled “gangs” by their critics, these associations have been likened to west coast gangs like the Bloods and the Crips, which according to many researchers, embrace violence as an essential component of their identity. By tracing the social, cultural, political, and economic underpinnings of these contemporary New York City “gangs,” the reasons why they have embraced an avowedly antiviolent platform are explained. By attempting to regulate unchecked neighborhood-level violence, these groups speak to the desire by inner-city residents to regain control over their everyday lives. At the same time, they call into question the popular notion that inner cities are spiraling out of control and that violence is essential to the gang experience.

**Key words:** Gangs, violence, drug markets, inner-city ethnography

## **GANGS AND VIOLENCE**

The American imagination is obsessed with images of the violent gang, which have poured into a flood of films, novels, plays, news stories, commentaries, and tabloid features. A procession that began with the showdowns of Jesse James and his peers was continued in Mafia shoot-outs and “rubouts” from Al Capone to the “Teflon Don” (John Gotti), the switchblade choreographies of “West Side Story,” drive-by shootings between the Bloods and Crips on the west coast, and (some say) law enforcement retaliatory tactics by the Los Angeles Police Department (LAPD). The same preoccupation marks

the scholarly literature. Researchers who make the implicit (or explicit) assumption that gang allegiance automatically leads to greater violence have advanced many reasons to explain the relationship between gangs and violence. The canonical typology includes such forms of violence as *instrumental or corporate* (Skolnick et al. 1989; Taylor 1990), *territorial* (Moore et al. 1983), *defense of honor and respect* (Horowitz 1983), *expressive or symbolic* (Conquergood 1992; Erlanger 1979), *racial/ethnic* (Brotherton 1993), *internally ritualistic* (Vigil 1996), and *sociopathic* (Yablonsky 1984). A peripheral type also occurs when the victim is not a gang member and is hurt as a result of predatory crimes or stray gunfire (Klein 1997). Another important area of gang violence to come under scrutiny from criminal justice agencies concerns the proliferation of weapons among members (Spergel 1985), which has been associated with gangs whose structures and boundaries are atrophying or whose sole purpose is the conquest of “market competitors” in the street economy. Prison, where many inmates suffer at the hands of peers and custodians, is another catalyst for gang violence.

Violence is often constructed as essential to the gang experience. Researchers have recently likened the “beatdown,” in which initiates run the gauntlet of established members to gain admission to the gang, to a “street baptism” and to male initiation rites in preindustrial tribal societies. Researchers also argue that this inaugural beatdown constitutes outward violence (the “gang bang” [see glossary at the end of this chapter for definitions of this and other terms]) turned inward and that both dramatize the need for protection and escape from fear, as well as release from “pent-up aggression born of trauma and rage” (Vigil 1996, p. 150). While addressing problems of youths’ gender and age role identity resolution, these ordeals also test the fighting skills and combative courage of newcomers. Accordingly, a gang is defined as “a territorially affiliated group of youths (typically organized into age-graded cliques) dedicated at least in part to fighting other similar groups” (Vigil 1996, p. 153).

There is no doubt that gangs have sometimes been guilty of heinous acts, and they are rightly accused of being involved in a wide variety of crimes, including drug distribution and major crimes of every type, and in violence against one another and innocent others (Cloward 1966; Cohen 1971; Fagan 1989; Geis 1965; Hagedorn 1998; Jankowski 1992; Klein 1971; Moore 1979; Padilla 1992; Thrasher 1936; Vigil 1988; Yablonsky 1984). This chapter, however, describes a contrasting situation among resurgent Puerto Rican gangs in New

York City. Using ethnographic methods and techniques, three variants of the Latin Kings gang are identified,<sup>1</sup> and violent incidents involving them are examined in historical and neighborhood-specific contexts. This chapter argues that, far from being senseless and random, violence not only has a structure and function but also, especially in the mid-1990s, has often been part of wider attempts by local residents to solve problems of social disorder at the local level. Instead of contributing to communal strife, the emergence of the Latin Kings appears to be, at least in part, an indigenous attempt to ameliorate out-of-control violence that antedated their formation. Ethnography is particularly well suited to probe changes and shifts in neighborhood-level violence because it can account for structural and institutional factors that set the stage for different types of violence. Indeed, this chapter posits that violent events can be truly understood only by interpreting them in the context of communities that render all social behavior meaningful. By examining violence from such a perspective, the utility and power of ethnography as an explanatory framework are revealed.

## METHODS

Since 1979 the authors have been observing and interviewing successive generations of minority youths in New York City's inner-city neighborhoods in ethnographic research projects. Ethnography is often employed to describe populations and social environments that are hidden from normal observation (Lambert 1990). It is indispensable when exploring emergent phenomena, as in this case, where the formation of a grassroots political movement was accompanied by myriad internal contradictions and a tremendous amount of misinformation supplied by media and governmental sources. Beginning in 1996, we have focused our investigation on the gang involvements of contemporary cohorts. We concentrated on the members of a "fence-sitter" (a gang whose members cannot decide what they want to do) chapter of the Latin Kings in Bushwick, Brooklyn, and especially on the comings and goings of its Third Crown, King Paz. This chapter provides initial findings from the study.

Ethnography is the study of contextualized behavior that is described and explained by researchers in a series of graduated contexts (from microlevel, to macrolevel, and back again) framed by social, economic, political, and cultural parameters. Unlike experimental

paradigms, ethnography requires a holistic perspective, and populations are examined in their natural environments. As such, neighborhoods as a whole are examined, and the direct observation and analysis of behaviors and practices at both the individual and group levels are thus able to be placed meaningfully in the context of a community. Research participants are observed in public and private domains, allowing for descriptions of the intimate, mundane, and extraordinary details of their everyday lives; the social contexts that frame them; and the manner in which they comport themselves and construct their identities.

The chief methodological tool for many ethnographers is participant observation, a process that entails becoming immersed in a community of individuals, observing and talking with them, and learning about their experiences and constructions of reality (Adler 1990; Agar 1996). Direct observations were made of the interactions among the Latin Kings and members of their families, neighborhood residents, and various types of law enforcement personnel, including beat officers and members of the New York Police Department (NYPD) Tactical Narcotics Team and the Warrant Squad. In addition to observations, tape-recorded ethnographic interviews elicited information on a wide range of topics, including demographics, childhood and family background, education and work history, drug use or distribution history, social networks, income generation and expenditures, participation in violent or criminal acts, impact of law enforcement initiatives, arrest and incarceration history, and the role and status of members in the larger community and in the gang.

One strength of ethnography is that it allows for the combination of different data sources and permits information to be cross-validated and targeted for followup and clarification. Many hours were spent discussing and reviewing field observations and information gathered through ethnographic interviews. Findings that seemed unusual or appeared to contradict prevailing wisdom became the topic of further ethnographic inquiry. By proceeding gradually and exhaustively from minute particulars to general sociological statements, the authors adhered to a rigorous process of constructing and testing hypotheses (Dumont and Gulati 1981; Glaser and Strauss 1967). Ongoing analysis of the data served to guide and sharpen further data collection and led to a deeper, contextualized understanding of social phenomena (Burawoy 1991). In this way, the authors were able to reconstruct the historical context of neighborhood-level violence and

build a framework for interpreting direct observations of violent incidents.

## THE DEMISE AND RESURRECTION OF GANGS IN NEW YORK CITY

Gangs have sometimes posed a serious threat to social order in nearly every large city in the United States (Spergel 1985; Thrasher 1936), but their history in New York City has differed somewhat from the national norm. From the 1950s to the mid-1970s, gangs were found in many of the city's ethnic neighborhoods (Gilbert 1988). Their ubiquity commanded the attention of social scientists (Becker 1997; Cloward 1966; Cohen 1971; Geis 1965; Matza and Sykes 1961; Miller 1958; Yablonsky 1984). The most common type was the territorially based youth gang, which was said to govern the social lives of alienated youths in affected neighborhoods.

This youth culture, however, was soon altered. In the early 1960s many New York City neighborhoods experienced a radical transformation that originated in the period's restructuring of global, national, and regional socioeconomic arrangements (Mandel 1978; Phillips 1990; Sviridoff et al. 1992). Neighborhoods that once had been populated by European Americans were rapidly evacuated and repopulated by migrants from Latin America and the Caribbean, where U.S.-directed modernization and development programs had transformed indigenous economies, causing malintegration between economic sectors, unemployment, and new waves of migration (Sassen-Koob 1989; Wallerstein 1974). As European Americans deserted the city, more than 500,000 manufacturing jobs fled the city with them, and as the city's tax base shrank, expenditures for public services were sharply reduced (Kasarda 1992; Mollenkopf and Castells 1991). Although a few large manufacturers remained, by 1996 the typical local company intermittently employed workers in nonunion, low-skill, low-wage, and high-risk jobs. The economy stopped guaranteeing economic prosperity and security and offered high unemployment and underemployment instead. Thus, on arrival in cities in the United States, a significant proportion of new immigrants were trapped in steadily deteriorating neighborhoods by unemployment and the lack of low-income housing. Newly arriving minority youths were attracted to drugs and the "fast" money circulating in drug markets.

The relationship among vanishing economic resources, youth unemployment, and gangs remains unclear. Many researchers believe that deindustrialization promoted all three (Cloward 1966; Hagedorn 1998; Klein 1971; Short 1996; Vigil 1988). Gangs became the routine organizational response by inner-city youth on the west coast and in the Midwest to the socioeconomic decline of the 1980s (Hagedorn 1998; Moore et al. 1983; Padilla 1992; Vigil 1988). But in New York City, gangs had been disappearing since the early 1970s.

Research on gangs in New York City was discontinued, except for the work of Campbell (1984), whose research was completed at the end of the gang era, and Jankowski (1992). Although Jankowski claimed that he had found many gangs during the 1980s, his work has been questioned by his peers (Fagan 1993; Klein 1997; Sullivan 1994). Genuine exceptions were the Chinese and other Asian gangs thriving in the atypical setting of Chinatown in lower Manhattan, where the “tongs” had long been active in the heroin trade and racketeering (Chin 1996). Elsewhere in New York City, however, drug distribution organizations had completely supplanted gangs as the primary units of association for younger persons in low-income, minority neighborhoods (Curtis and Maher 1992). The evolution of street-level drug markets (heroin and marijuana in the 1970s and cocaine and crack in the 1980s) and the societal responses to them (an enlarged police force, more incarcerated persons, drug-related stigmatizations) had transformed the urban landscape on the east coast (Belenko et al. 1990; Hamid 1990*b*; Sviridoff et al. 1992; Zimmer 1987).

In New York City, criminal drug distribution had been vertically organized since the prohibition of alcohol and was the exclusive domain of European-American gangsters. Heroin, an illicit substance since 1914, was sold by them in the 1920s and 1930s on Manhattan’s Lower East Side (Courtwright et al. 1989). After World War II, African-American subordinates were franchised to distribute heroin in their neighborhoods. In the 1950s drug distribution and use were widely suspected to be part of a subversive Chinese communist plot to undermine the United States, and a series of harshly punitive laws were enacted (Courtwright et al. 1989; Musto 1987). At an infamous meeting in upstate New York in the late 1950s, organized crime “dons,” wishing for greater legitimacy, withdrew their “families” from drug distribution (although not all families complied with the edict). Puerto Rican freelance distributors filled the vacuum. As heroin injecting grew to epidemic proportions between 1964 and 1972,

Puerto Ricans quickly cornered street-level sales in many neighborhoods, and their incipient organizations grew in size and complexity (Preble and Casey 1969). When the “epidemic” ended, a few Puerto Rican “owners” (of drug businesses) had consolidated the market and, throughout the late 1970s and early 1980s, served an aging, increasingly impoverished clientele. Located in selected Latino neighborhoods, these businesses remained an exclusively Puerto Rican enterprise. In the Williamsburg section of Brooklyn, for example, four Puerto Rican owners employed a street-level staff of Puerto Ricans exclusively (Curtis and Maher 1992).

Drug epidemics typically traverse a series of developmental stages, over the course of which the identities of users and the composition of drug-distributing groups change (Hamid 1992). Markets for smokable cocaine unfolded rapidly during the 1980s. A brisk sequence of forms of consumption (from freebasing to smoking a “stem” or “wulla joint”) corresponded to a turnover in locales, forms of cocaine, and methods of distribution. Eventually, the distribution of cocaine in many Caribbean-African and African-American neighborhoods was undertaken by freelance distributors, while others hosted vertically organized, hierarchical businesses (such as the Jamaican “posses”). In many Latino neighborhoods, however, the existing Puerto Rican-owned heroin- and cocaine-distributing businesses grew into monolithic enterprises that tightly integrated wholesale, midlevel, and street-level markets.

Law enforcement initiatives affected the succession of ethnic and national groups in drug markets. As police campaigns clamped down on the Puerto Rican owners or moved them out of their old selling locations into new neighborhoods, Dominicans entered the competition and displaced them. A deep rift between a Dominican ownership and a disaffected Puerto Rican labor force soon tore apart these monolithic enterprises (Curtis and Maher 1992).

The campaign against crack markets mounted steadily after the mid-1980s. In 1984 the NYPD launched Operation Pressure Point on Manhattan’s Lower East Side (Mulgrav 1985; Zimmer 1987). When it was learned that the death of a police officer had been commissioned by a street posse in Queens in 1988, Tactical Narcotics Teams (TNTs) were created. TNTs were adopted by the NYPD in 1988 as its premier method against street-level drug markets, and they were replicated in four of the city’s five boroughs. By 1990 more than 700 officers had been assigned to them, and in that year, they made

more than 24,000 arrests, flooding the courts and prisons (Belenko et al. 1990).

In the early 1990s cocaine smoking stopped appealing to the uninitiated (Hamid 1990a). Many long-term users terminated use as a result of maturing out, rehabilitation, illness, death, or incarceration. Street-level crack markets contracted in size and geographical spread and were eventually reorganized as “supermarkets” restricted to relatively few (mainly Latino) neighborhoods, such as Washington Heights, East Harlem, Hell’s Kitchen, the Lower East Side, Bedford-Stuyvesant, Bushwick, and Mott Haven, or located in some of the identical locations in which street-level heroin markets had also persisted since the 1960s. The heroin and cocaine markets were thus combined.

TNTs enjoyed a great benefit from the contraction and concentration of street-level crack cocaine markets. They were able to focus their efforts on fewer precincts and still maintain the same high number of arrests (about 400 per month per unit) previously achieved within a much larger geographical area. For example, more than 8,200 persons were arrested between 1988 and 1992 in Bushwick alone. Police vans sometimes evacuated the entire local Puerto Rican drug labor force. A common joke was that “Rikers has turned into a Bushwick (or Williamsburg, or East Harlem) block party” (Curtis and Sviridoff 1994). In Rikers Island, the young males of the neighborhood were penned in on one side of the visiting room, while the young females and children sat in front exchanging gossip about recent arrests, sentences received, and mounting family pressures.

After an absence of 10 to 20 years, gangs were revived in New York City. The Latin Kings served the incarcerated young men, the Latin Queens the young women and their children. Gang life had been revived among a population of convicted drug distributors and users after a long dormancy. Since the late 1980s teenagers and young adults have flocked to it, especially in Latino communities under the banners of the Latin Kings, Spanish Kings, Ñetas, La Familia, Latins Don’t Play, Papi Chulos, and Dominicans Don’t Play. In addition to these major gangs, with many chapters and large memberships, were myriad “baby gangs,” with members ranging in number from a mere handful to 100 members, that coalesced for variable lengths of time, sometimes to reach specific goals, before dissolving and perhaps delivering their membership to one of the larger gangs. Members

of each gang are identified by various codes, including different combinations of brightly colored beads and hand gestures.

Criminal justice personnel were alarmed because the reliance on prisons, rather than discouraging or restricting drug use, drug distribution, or crime, had instead facilitated social movement among the prisoners and had permitted them to disburse and augment their cultural and political power. The Latin Kings were singled out for special surveillance because the gang was believed to be an ultraviolent, supercriminal organization.

## RUNAWAY, OUT-OF-CONTROL VIOLENCE IN NEIGHBORHOODS

While gangs and drugs were alternating allegiances for youths in New York City from the 1970s to the present, the level of violence in neighborhoods was also rising, as a result of the phenomena described below.

### Destruction of the Infrastructure

If incivilities or quality-of-life offenses can lead to greater and more serious offending (Kelling 1989; Reiss and Tonry 1987), the physical transformation of neighborhoods, which reminded many observers of “Dresden after the war” (Hamid 1990*b*; Vergara 1991; Wallace 1990), has had multiple negative effects. In Bushwick, the south Bronx, and other neighborhoods, block after block of apartment buildings were abandoned, and some homeowners, seeking to collect insurance monies when they could not sell their houses, torched them. By 1977 more than 1,000 lots in Bushwick—fully one-fifth of available space—were empty (Curtis et al. 1995). The section had become an urban wasteland whose charred, derelict landscape was matched by a frontier mentality where confrontation and violence were commonly used to impose order and resolve disputes.

The intimate contexts in which human beings are socialized and discover their self-worth were dealt the greatest blow. Because of the shortage of affordable housing, families were forced to “double up” and “treble up,” and authority relations were undermined within households (Maher et al. 1996). Instead of being cohesive units, families were fractured, setting genders and generations on a collision course with one another. In some households, while grandmothers barricaded themselves and their meager valuables behind locks within

their single bedrooms, their sons and daughters, mostly 30-year-olds, roamed the rest of the apartment bingeing on crack and alcohol. Their children, ranging in age from newborn to 16 to 17 years old, had their own difficulties, which in addition to teenage parenthood and dropping out of school, included avoidance of hard drugs (and gang membership).

The high turnover of tenants and homeowners weakened, if not completely discontinued, voluntary associations. The disinvestment in schools and community emptied PTAs, clubs, church groups, and grassroots political groups. Thus, the informal controls that define and protect neighborhoods were slackened (Curtis and Maher 1992).

### **Drug Supermarkets**

The conversion of drug markets to a few supermarkets also precipitated great tumult. Drug distributors have long commanded attention (Fagan 1989; Goldstein 1985; Hamid 1990b; Skolnick et al. 1989) for their unprecedented levels of and novel approaches to violence, including the infamous “Colombian necktie,” the use of box cutters to slash faces, and promotion of the 9mm pistol to the status of cultural icon. Ethnographic research in the past decade, however, has shown that there is a wide variety of distribution styles and that the role and incidence of force vary greatly among them (Bourgois 1989; Curtis et al. 1995; Hamid 1990b; Maher and Curtis 1994; Williams 1989). Some markets earned reputations for controlling violence (e.g., Hamid’s [1990b] marijuana distributors, Williams’ [1989] crack dealers), while others employed violence regularly and systematically (Curtis and Maher 1992; Taylor 1990).

A quantum leap separated these usual markets from the drug supermarkets described above, in which large corporate-like organizations effected street-level drug sales, and since institutional and neighborhood-level restraints had already vanished, these supermarkets completely disregarded the sensibilities of residents in doing so. They also undermined the prosperity of the communities that hosted them, just as their counterparts in the formal economy (large corporate retailers that drive out mom-and-pop operations) are often accused of doing. While their sole benefit consisted of low-level, dead-end jobs for youths, the damages included plummeting property values, a greater incidence of drug misuse, and high rates of incarceration. But the most crippling legacy was violence.

By 1992 one Puerto Rican and three Dominican owners ruled over crack distribution at the northern end of Bushwick. Each had a trademark represented by the color of the tops of the crack vials they sold: white, blue, brown, and pink. Dominican families monitored the day-to-day operations of the largest three. Younger family members and close nonkin "associates" directed street sales, while older family members, entirely removed from the street scene, were the "executives" (owners and "chief executive officers" of corporate-like drug businesses). When there were not enough family members, owners employed persons who shared a similar background. The practice earned them the resentment of street-level workers, particularly Puerto Ricans who had controlled distribution throughout the 1970s and early 1980s (and had similar policies), only to be toppled by the Dominicans in the late 1980s. The rivalry that had long existed between Puerto Ricans and Dominicans in New York City was thus sharpened in the drug business. Henry, a Puerto Rican heroin seller who subsequently became a member of the Latin Kings in Rikers Island, discusses the animosity in 1992:

The Puerto Ricans and Dominicans are pretty separate. They got their own clubs, you know, their own crew. Some of them socialize, you know . . . with people that are not in the drug business. They might work together in the same factory, same jobs. Some I could say they're tight. But when it comes to the drug business, they're not tight, you know. There's no trust whatsoever, you know; and it's always remorse and always backbitin' and they're always tryin' to get over on each other.

Non-Latinos and heavy drug users were marginalized and victimized even more severely by these organizations. Bruce, an African-American injection drug user who sold crack for the four owners, was routinely beaten up by his Latino managers. Moreover, they would never promote him. As he explains: "The street workers, the guys that actually pitch the stuff, those could be all kinds of different guys. But it's highly unlikely that a guy like myself could become a manager. They have something against anyone who uses drugs even though they sell it. It's very illogical, but that's the way they are."

Law enforcement activity against the drug trade daily depleted the supply of eligible Latinos, who were replaced by African Americans, European Americans, and heavy drug users. The gulf separating management from labor widened, and their already contentious and

adversarial relationships became even more distrustful and violence prone. Because they resented their harsh and dangerous conditions of labor and the disrespect their managers showed, many street-level sellers took every opportunity to abscond with the drugs. They fully expected physical punishment for the transgression. As Doc says: "I haven't been down here recently because, well, 'cause I ain't got they money yet. And the last guy I seen that had got busted, or jettied, or whatever, he came back months later and he didn't have the money, and I seen them bat him down. They broke his ribs; they broke his lungs."

José also explains: "If they catch the people that are cuttin' out with their product, they either make them work for nothing or they'll break their arm, or break their leg. Forget it, man. They hurt . . . they get a beating. They break their legs or an arm. But now if anyone hits you, they all hit you. They all hit you."

In effect, although brute force or the threat of it is the ultimate means distributors have to enforce rules, a business is ruined when it invites police attention too frequently. Accordingly, sensible or successful distributors avoid or minimize its use. But Bushwick's corporate owners were reckless. Violent acts were more common in their markets because of the divisions and animosities that rigidly separated different levels of the organizations, because the owners did not live in the neighborhood and did not have to witness or confront the aftermath of their deeds, and because they could easily relocate supplies to outlets they maintained in other neighborhoods. Indeed, owners encouraged their managers to regularly use public displays of force as a way of intimidating untrustworthy employees and to send the message that the owners should not be crossed. For example, one owner hired an "enforcer" who strolled around the neighborhood with a baseball bat on which he wrote the names of his targets. After punishing them, he rubbed off their names.

In the Bushwick of the early 1990s, face-to-face or "man-to-man" confrontations between individuals were replaced by humiliating group beatings, or gang bangs. Their unrestrained brutality affected local adolescents, who regularly witnessed these beatings and who sometimes also participated gratuitously in beatdowns and other bloody episodes in which they had no stake. They simply saw someone being chased and, with smiles on their faces, picked up their baseball bats or bicycle chains and joined the chase. For them, "fun" was no longer spraying graffiti, playing ball, or dancing; it was the

number and severity of beatdowns they administered daily. Drug supermarkets made these atrocities an unremarkable, commonplace feature of everyday life.

As described earlier, TNTs were adopted by the NYPD in 1988 as its premier method against street-level drug markets in four of the city's five boroughs. Although any police operation that targets street-level drug markets may prompt the use of force, as people resisted being arrested or attempted to flee, TNTs were innovative and conceived many unusual strategies that deeply alienated neighborhood residents. For example, when "sweeping" (ridding an area of drug sellers and users by systematically searching everyone on the block) the main drug-selling areas, they would cordon off both ends of a street and require everyone in between to lie down, regardless of who they were. This tactic nearly always yielded a handsome body count of arrests, but it also obliged elderly grandmothers and young children to grovel on the asphalt while being roughly searched, which enraged many residents.

In the summer, local police officers systematically harassed drug users who loitered near the major drug-selling locales. Early in the morning when the drug users had fallen asleep on the sidewalk, foot patrol officers would routinely rouse them with kicks and order them to move. Sometimes the kick simply nudged the unfortunate awake; at other times it was meant to cause pain. So habituated were the police officers to this activity that they continued it even when their behavior was recorded by video cameras. They also responded with an overwhelming show of force at almost any infraction, be it a drug user's, dealer's or passerby's. As Pablo relates:

A young Latino, about 25 or 30 years old and weighing about 120 pounds, was being arrested by two officers. They had him in a choke hold, and he started bleeding through his nose. I informed the police officer that the guy was bleeding through his nose and he couldn't breathe. His reaction was, "Hey, I can't breathe either." As the crowd got bigger, they started to notice the guy was bleeding through his nose, and people were saying things to [addressing insults at] the cop. He sent some sort of message into his walkie-talkie, and within 30 seconds there were dozens of cops on the corner. They were all there to arrest one guy who apparently had attempted to steal a bicycle. It just looked ridiculous, but the situation could have easily gotten out of control.

By late summer 1992, the populace was close to insurrection, and television and newspaper crews came to interview unruly crowds who were protesting the indiscriminate police shootings and beatings of youths. Police had responded in full riot gear, and other residents had pelted them from the rooftops with bottles, debris, and hateful epithets. Apparently thinking that beleaguered drug distributors were fomenting the neighborhood's growing hostility toward them, the police mounted yet another major offensive against street-level drug markets in September 1992. They stationed a mobile trailer in a nearby park to serve as the base of operations for more than 300 additional uniformed officers; for the next 18 months, Bushwick was virtually occupied by the small army of police.

### **LOCAL RESPONSES TO THE VIOLENCE: YOUTHS IN RETREAT**

In 1994 a household survey of 18- to 21-year-olds in Bushwick measured instances and perceptions of local violence (Friedman et al. 1997). The survey revealed that:

- 32 percent of the young people (47 percent of males) had been beaten up
- 25 percent (40 percent of males) had been threatened or stabbed with a knife
- 20 percent (23 percent of males) had been caught in a random shoot-out
- 19 percent (27 percent of males) had been threatened or shot at with a gun
- 35 percent (37 percent of males) had been mugged or robbed with a threat of bodily harm

The endangered youths made remarkable adaptations. Some withdrew from public forums to the relative safety of home. In focus groups and interviews conducted by the researchers during the winter of 1993 to 1994, many respondents said that they were so fearful of random or police violence that they no longer spent much time in parks, playgrounds, stoops, or other places where they had traditionally "hung out." Indeed, the question, Where do you hang out? seemed to offend them. As Javier, a young Latino who participated in the research, commented:

OK, I hang out. I chill out now and then with the young guys, but it's rare. Most of the time, during the week you

find me with people like 30, mid-30s, 40 years old, and I'm chilling with them. I feel safer, you know. I don't have to deal with what's going on in the street. Once in a while I'll hang out with one of the fellas I grew up with. Maybe if I bump into him. Like if I'm walking down the street, and I haven't seen him for a while or I'd see what he was doing and I was avoiding him. Maybe I'd hang with him for a couple of minutes, or at the most for an hour. But then, you try and draw back, 'cause you don't want to get caught up in what he's doing, especially if the police are looking for him.

## RISE OF THE LATIN KINGS

Not all youths in Bushwick were scared into hiding behind closed doors. Some took a much more proactive stance. By 1993, following the massive police initiative of September 1992 in which hundreds of neighborhood youth were jailed, sizable chapters of the Latin Kings and Ñetas formed and asserted their control over some blocks, especially those where there had been large street-level drug markets and unchecked violence. Predominantly of Puerto Rican descent, they reported that they had experienced a genuine rebirth, and in leaving behind the past, their new goal was to "uplift the Latino community." As former street-level drug workers who had suffered at the hands of their Dominican bosses and the police, they were disillusioned. Although they had long realized their limitations in U.S. society, the sweeping arrests had also taught them the shallowness of the drug distribution organizations that had employed them. The Dominican owners did not bail them out of jail, hire lawyers, look after family, or compensate them for their time in prison. The owners remained indifferent to Puerto Rican sensibilities, although mainly Puerto Ricans suffered the brunt of these law enforcement actions. As Ariel relates:

During my time on Rikers Island, I was going to court. My bail was only \$5,000. My foster mother spoke to the [Dominican] owner and asked if he could bail me out. At that time, I had \$10,000 out there in the streets that different people owed me. He said, "Well, whoever works for me and gets arrested has got to be a man. Do the crime, do the time." Eventually, I came home. [But] I wanted to get even with this guy 'cause he played me. All that time, I could have been at home. I could have fought the case outside. Five thousand

dollars, you're telling me that you couldn't bail me out? I don't want to hear that.

For many former street-level drug distributors like Ariel during this period, going to jail—Rikers Island—capped many years of frustration, victimization, and abuse. In jail, membership in the Latin Kings offered Ariel repudiation of the past and redemption.

Before I was a King, I was a knucklehead. My temper got me kicked out of school. I used to fight a lot with teachers. I used to sell drugs a lot inside school. During my time on Rikers Island, I was in the position of changing myself: stop selling drugs. I started seeing the light more and wanted to follow a more spiritual path. It's not all about selling drugs anymore. It's not all about taking. It's all about giving back to the community. I took so much; now it's time to give back.

Membership in the Latin Kings brought with it a list of benefits, which are described below.

### **Social Organization Among Youth**

The Latin Kings imposed organization, government, and order on atomized, marginalized individuals. In New York City, the Latin Kings are organized in subdivisions or “tribes” (which are somewhat geographically based, but open to members who live outside the area), each of which is governed by five “crown” (leadership position) members. The various tribes are united by and answerable to a five-member, citywide council of “Supremas” (paramount leaders of the Latin King/Queen nation in New York City). As Manny describes the King’s structure:

The First Crown is the head, the brain of the body. His word is final; he makes the last decision. The Second Crown is like an advisor to the First Crown. There's a chain of command, and not everything that happens in the tribe will make it up to the First Crown. So, the Second Crown is like a gatekeeper who will decide whether something is important enough to bring to the First Crown. If it's not so important, he'll take care of it himself. The Third Crown is the Sergeant at Arms. He's responsible for holding guns, ammo, knives. If any war breaks out, he automatically becomes First Crown. He is the

general, but he's also responsible for being a peacemaker. The Fourth Crown handles the tribe's money, collects dues, and monitors attendance at meetings. The Fifth Crown is the spokesman who communicates between Crowns and the general membership.

### **Peace in Prison**

The Latin Kings solved many of the difficulties of young Puerto Rican men and women who were incarcerated. The most pressing was protection from other inmates. For a first-time arrestee, membership in an organization that applied blanket protection throughout the prison system was a blessing. It bestowed status and prestige, prevented victimization (including sexual violence), and allowed peaceful arbitration of disputes with other members.

### **Peace at Home**

Gang membership was also advantageous on return to civilian life. For members whose households were chaotic, the gang functioned as an alternative family that prescribed rules and justifications for behavior, thereby bringing order and structure into potentially unmanageable social and emotional situations. As King Paz, Third Crown of the Latin Kings, says:

We're trying to get into doing the right thing. We don't want that name "gangbanger." Everybody thinks of the Latin Kings, and they think of the Kings of the early '60s, how they used to have big motorcycles, chains, and you know, Savage Skulls. We want to get rid of that name. We've been doing it so far. In New York City and everywhere, we've got good kids and bad kids. We're lucky. We have a few more good kids than we do bad guys. We got more positive guys than gangbangers. So far we've been controlling the ones that are gangbangers and calming them down, and they chill, and they stop off the corners, they go to school or get a job. Any kind of paying job as long as you're going there for 8 hours. More and more guys, they want to keep their crowns, and they're willing to go out there and get a job. So I see more and more guys are switching now. If more and more guys are switching, that means we're doing something right.

## **Forestalling Intergang Violence**

The Latin Kings in New York City, who generally enjoy cordial relations with other gangs like the Netas and the (mainly African-American) Zulu Nation, are significantly different from the gangs that researchers have characterized as “fighting gangs” (Jankowski 1992; Vigil 1996). They have been involved in only a few incidents of group or intergang strife and are building a positive image in Latino neighborhoods by performing charitable and civic-minded work such as cleaning hospital lobbies, supporting Latino political candidates, caring for people living with AIDS, and feeding homeless people. However, many individuals steeped in street “hustling” continued to be involved in drug distribution and other illegal sources of income. When arrested, the police and media tended to interpret their acts as “gang related.”

## **THE WORK OF THE THIRD CROWN: CONTAINING VIOLENCE**

In a Latin Kings chapter of any type, the Third Crown monopolizes power, authorizes its use, arbitrates disputes, and is responsible for the firearms members own. Accordingly, it was thought that the level of violence or violent orientation in a chapter could be gauged by carefully examining the actions of its Third Crown. A heavily muscled 300-pounder and a visually imposing sight on the street whom visitors could scarcely avoid, King Paz was perfectly suited for this research task. After gaining permission from his brother, the First Crown, King Paz readily agreed to join the project as a respondent.

King Paz was 29 years old when he joined the Latin Kings in Rikers Island. He had been the owner of a successful medium-size crack business in Bushwick and also sold guns. He had avoided arrest until early 1995 when a street-level seller informed on him to the police in return for a reduced sentence. He was married, had a 1-year-old son and a 12-year-old daughter from an earlier marriage, and portrayed himself as a “family man” (his term to describe himself as doting on family and domestic affairs) in the neighborhood. Until his arrest, he also held a full-time job maintaining and repairing sophisticated medical diagnostic equipment.

On his second day in Rikers Island, King Paz intervened in a dispute and unwittingly helped the First Crown of the Latin Kings in his cell block:

I found out that he was the First Crown of the Latin Kings. He said Latin Kings believe in positive roles and helping each other out through good times or bad situations. I said, "You know, that is what I am looking for. I am looking for a group of friends who are loyal to each other." So that is what I am looking for, and I wanted to become a Latin King. There is a lot of loyalty in there. A lot of loyalty.

When he returned to the neighborhood, King Paz was elected by the members of his Tiger Tribe to be the Third Crown. His 24-year-old brother was the First Crown. Being the Third Crown of this chapter required rational decision-making abilities and remaining on perpetual call. The chapter was the fence-sitter type, and members were torn between pursuing criminal activities or becoming a mainstream youth movement. While many newly converted Kings had sworn allegiance to the "nation," they were accustomed to resolving both real and imagined disputes violently. King Paz complained that the impulsiveness of younger "brothers" (gang members) made his job stressful:

We got boys that are very loyal, and they're willin' to go the extra mile, but they make bad decisions. Like, you said, "Oh, that guy dissed me." And you told a bunch of guys, "Let's go beat him up." But just because he looked at you, OK? And all of a sudden, this guy that you tell me about pulls out a gun and shoots two of your people. You had others jump him without knowin' if he had a gun on him. There was no probable cause. There was no reason.

King Paz, a young man whose wife and children lived in an apartment vulnerably located on the first floor and who frequently walked about the neighborhood unprotected, was terrified of gunplay. It threatened his friends and the reputation that the nation was attempting to build in the neighborhood. Younger members were continually requesting its use. But in his view, the job of Third Crown was not to wage war and authorize the use of violence, but rather to keep it in check. As King Paz noted:

When I see my boys acting as though they're a dangerous Rottweiler [big, fierce dog], I'm the one that puts a choke on them. In the last few months, I've squashed a bunch of disputes. For example, up on Fulton Street there was a little squabble with the Spanish Kings. I thought it was stupidity.

One Spanish King fought a Latin King from the Bronx. Both of them took out razors. Both of them got cut. The Latin King went to the Crowns in the Bronx and wanted to have war with the Spanish Kings on Fulton. I'm saying to myself, "That's stupidity." They both got cut, they both got their thrills, now let's leave it alone. I went down there, spoke to their heads. I had it squashed; that was it. I gave my King a fine and put him on probation.

Preventing the nation from being involved in violent disputes was an exhausting job, but King Paz took great pride in his reoriented life and the successes that he and the nation enjoyed through his efforts:

I remember before, I used to do all the drugs in the morning and sleep all day. Well, I got a responsibility now. I think by me bein' here, I make a difference though. 'Cause people don't think with their fingers. 'Cause—Have you read the papers, "Latin King shot." No. That means I'm doin' my job, man. I mean, I have nothin'. So far, I haven't read no papers that said, "Latin King involvement." We stay outta the press.

Once a gunrunner himself, King Paz closely monitored all firearms his tribe owned. He realized that even a single incident involving gunfire could have far-reaching implications, and he actively worked to avert it:

Ninety-nine percent of the time we talk it out. And luckily, at this point, thank God, no shoot-outs. I'm gonna tell you something. The way things are happening, whoever lives by the trigger, they're in jail. I have not seen one guy commit a crime shooting and is still walkin' the streets 2 weeks later. You have to be careful with a trigger finger. I don't want it near me. 'Cause if you have got a trigger finger, you could turn around and shoot all of us.

When King Paz could not resolve a dispute by talking it out, he still avoided bloodshed by assembling a group of aides—his "pearls"—to make an intimidating show of muscle and force:

Nobody's allowed to do any power moves. No physical contact with another human being, unless I know about it. And approve of it. Now before I approve it, I have to investigate. I'll go get my pearls, which were the guys next to

me. They have to be completely drug-free, alcohol-free, have to have good muscle. If you can't fight, you're no use. I know how to pull a trigger. I don't need that. I need guys to fight clean.

Sometimes these efforts backfired, as suggested by notes taken while debriefing a group of Kings immediately after this incident occurred:

King Vale had broken up with his wife sometime in February 1996 and had left her and their children in their Brooklyn apartment. When another King reported that she was seeing another man, King Vale went to the apartment to confront her. When King Vale arrived at the apartment and knocked on the door, he heard his wife say, "Oh my god, it's the baby's father." King Vale was upset that his wife, after 3 short weeks, had already moved someone else into their apartment. As the three of them started to argue in the doorway of the apartment, the boyfriend pulled out his gun and cocked it. King Vale, scared that he would be shot, ran from the scene and went directly to King Paz for advice and assistance. For one thing, he had no weapon himself since the Third Crown had his .38. King Paz decided that a large group of Kings would go to King Vale's apartment, disarm the boyfriend, beat him up, and evict him. When they reached the apartment and King Vale knocked on the door, the boyfriend immediately realized that there was a large group of people outside. Arguing with King Vale, he drew him into the apartment and pulled his weapon, shooting King Vale twice (once in the chest and once in the leg). The boyfriend ran out the door, jumped over the banister to the lobby below, and escaped through the front door of the building. The Kings gave chase and caught the boyfriend several blocks away. He had already jettisoned his weapon. The Kings beat him, and one slashed his face with a box cutter. Upon returning to King Vale's apartment, they found him dying. Hearing sirens (shots had been fired, someone had called the police), they all ran from the scene. Later, they learned that King Vale had died. His wife had tried to protect her lover by telling the police that the Latin Kings had shot King Vale. According to her, her boyfriend had been the innocent victim of a violent husband and his gangster friends. Fearing that their reputations and Mrs. Vale's accusations put them at risk of

arrest, they went into hiding and asked a third party to give a true account of the murder to detectives.

His failure to resolve the crisis dispirited King Paz and led to further disenchantment with the direction that the Latin Kings were taking:

I have no privacy anymore. I have no energy. I get up at one o'clock in the morning, run out of the house, get up at two o'clock in the morning. That's why my white blood cells are down, 'cause I haven't been eating right. All this trouble is renting space in my head. While all that's going on, when the guys were chasing the kid and cut him, some (\*\*\*\*\*) decided to do a hit on Atlantic Avenue and shot a big drug dealer. Now my guys bump shoulders with these guys that killed the dealer. They [the police] try to blame that on us, too. Now I'm like, "What the (\*\*\*\*\*)? Every homicide that goes on is us now?" I went to Long Island to clear my head because I was really stressed. So I'm like, "Oh (\*\*\*\*\*) , now I got to worry about the police. I got to worry about these guys trying to make an open season on Latin Kings." I don't even know where to start.

King Paz had realized the magnitude of the effort he had been attempting. Although he had done his job exceptionally well and was expected to rise in the ranks of the Latin King hierarchy, it had taken a heavy personal toll. Still unemployed after his return from prison, he had continued his crack business halfheartedly, convinced that he was violating the Latin Kings' doctrine and endangering his family for a dead-end career in doing so:

I have no Kings working for me in the drug business. Kings that sell drugs cannot wear their beads. He has to take them off. Mandatory. Put them away. Don't even have them with you. I don't even have mine. When you do something dirty, don't make it obvious who you are. Always represent the nation when you are walking the straight path, like when I am walking with my family going shopping. I am doing a positive thing, I am doing it with my family, but what I am doing now is negative, so I try not to advertise it.

At the end of 1995, King Paz sold his business to a group of Dominicans and took on the "job" of Third Crown full-time. But the Latin Kings offer no monetary compensation, and King Paz and his

wife sought frantically for jobs. In March 1996 King Paz found one as a salesperson in a surgical supply store in Manhattan, but after a month the owner could not afford to keep him. In May 1996 his wife applied for welfare benefits, and he was tempted to resume selling drugs. The Latin Kings were a noble cause, but they did not pay the rent or buy meals. Besides, although his role was a mediator of violence, he risked being identified by the police as a perpetrator. By the end of spring 1996, the pressures of the job had nearly become too much, and King Paz was considering giving up his position:

I know guys are looking at me to be elected First Crown, but I'm going to give these [touching his beads] up myself. It's too much stress. The position of Third Crown is like being involved with everybody's financial problems. I'm hearing every marriage problem. I'm hearing every problem like when a guy goes to the corner where he's not supposed to be at, you have a fight and you get jumped. I'm the one that they come to. If I wanted that kind of a job, I could have gone to the precinct and put a badge on. At least they'd give you a gun. And I'd get benefits and a pension, too. Yeah, so I'm not going to do this no more. I'm just going to live my life. They want more devotion, more than you got. They ask you for too much now. They're outrageous. They asking for more of your time; I say "Listen, man, I got a wife." That's the other thing—I had people coming in and out of my house. Get the (\*\*\*\*\*) out of here!

At the time of this writing, King Paz remained the Third Crown and a hard-pressed, discouraged peacemaker in Bushwick.

## DISCUSSION

Despite a fascination with violence that has characterized Americans since this Nation's inception, insight into the antecedents, meaning, and significance of violence has remained rudimentary. In the past 15 years in particular, gang- and drug-related violence has spiraled to unprecedented levels and has generated increased scrutiny by social scientists, policymakers, and the media. Although social scientists have proposed various taxonomies of violence that begin to differentiate between qualitatively different types of events, policymakers justifiably bemoan the lack of authoritative, indepth knowledge that might help guide sound decision making.

The incidents of violence among members of the Latin Kings and similar organizations in New York City in the mid-1990s are emblematic of the difficulties in understanding and responding to violence in an informed and effective manner and underscore the importance of ethnography as a tool that allows social phenomena to be interpreted in their appropriate social contexts. Although violent events in which gang members have participated either as perpetrators or victims may be shoehorned into several of the taxonomies developed by researchers, clearly this does not tell the whole story. Indeed, violent events examined from an ahistorical, decontextualized perspective are likely to provide a skewed picture that substantially misrepresents reality. This was precisely what happened with contemporary “gangs” in New York City.

At first glance, the “gang” phenomenon in New York City was paradoxical. It had occurred precisely at a time when crime and violence had fallen to unprecedented lows across the country, especially in New York City (Butterfield 1997; Krauss 1996). The soundbite-driven, reductionist analyses by the media showered praise on the mayor and his police department for achieving what many had thought impossible in the inner city, and most agreed that the growing “gang problem” was a potential “fly in the ointment” in improving New Yorkers’ quality of life rather than a part of the solution to the problems of crime and violence. On the surface, it appeared that the mayor, police, and media were correct: Members of the Latin Kings (particularly those who had come from the prison system) had indeed participated in violent episodes, some of which were quite gruesome (Agus 1995; Henican 1994; Tabor 1994). What “official” and media accounts failed to provide, however, was an understanding of how the Latin Kings were transformed in the early to mid-1990s, particularly as the organization moved from jails to the streets, and the significance of these types of organizations in neighborhoods that had been characterized by out-of-control violence over the past several decades.

The young men and women who grew up in violence-ravaged neighborhoods and who joined the Latin Kings and Queens in the early to mid-1990s did not experience a complete metamorphosis overnight. For many, violence had been the common coin of dispute resolution, and they found that old habits were hard to break. Yet the tone and meaning of their oral and written statements and the actions of many Latin Kings were avowedly antiviolence (including domestic violence). If, in trying to bring peace to their neighborhoods,

they sometimes resorted to the use of force (a privilege that the state jealously reserves for itself), they nevertheless engaged in it far less than the corporate-style drug distributors whom they displaced from the street corners. Using ethnographic methods and techniques, the historical and contemporary dimensions of neighborhood violence indicate that the emergence of the Latin Kings and other forms of grassroots political mobilizations did not simply represent an alteration in the form violence took, but rather signified an attempt to repudiate and restrain the legacy of unchecked violence that corporate-style drug distribution and antidrug actions had inflicted on neighborhoods. Without an ethnographically based understanding of the community context in which violence occurs, the actions of the Latin Kings and other perpetrators of "crime" will remain disconnected and misrepresented events that are too easily pigeonholed into categories that enable the pursuit of repressive or regressive political agendas.

## NOTE

1. Some "chapters" are of the *youth movement* variety and interpret "uplift of the community" as the promotion of education, health, and peaceful political action. Others, or *criminal* chapters, seek advancement "by any means necessary" and engage heavily in drug distribution and other criminal activity. Most, however, are *fence-sitters*, unable to decide between these two ideologies.

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## **APPENDIX. GLOSSARY**

Associate (noun): Managerial-level worker who supervises the hand-to-hand sellers of drugs

Colombian necktie (noun): A manner of killing a person whereby the throat is slit and the tongue is pulled through the incision

Fighting gang: gang that features fighting with other gangs as a primary criterion for membership

Gang bang (noun): A gang's fight with a rival gang

Hustle (verb): To generate income through a variety of means, including employment in formal, informal, and illegal sectors of the economy

Jet (verb): To run away from; often used in a negative fashion (e.g., refers to the action of someone who runs away with the organization's drugs)

Nation (noun): Term used by Kings/Queens to describe their “association”

Owner (noun): A person who runs a drug business

Pearls (noun): Kings who do not hold leadership positions but who are known for their prowess in a particular arena and who are sometimes called on to exhibit their expertise

Posse (noun): An organization of cocaine or crack sellers (Jamaican origin)

Stem (noun): A glass tube used for smoking crack

Supermarket (noun): A street-level drug market characterized by the presence of many drug-selling organizations offering a variety of products to a large, visible pool of anonymous buyers

Tong (noun): Chinese “associations” or gangs whose existence predates the migration of Chinese to the United States

Wulla joint (noun): Marijuana cigarette laced with crack; sometimes smoked instead of a “stem” to curb one’s desire to compulsively smoke crack

# **Chapter 8. Access and Adherence to Combination Antiretroviral Therapy for HIV/AIDS in Injection Drug Users: A Social Course Perspective**

*Norma C. Ware and Toni Tugenberg*

## **ABSTRACT**

New, highly potent medications, together with other advances, are turning AIDS into a disease one lives with rather than dies from. Perhaps the most daunting challenge for those attempting therapy with these new drugs is adherence. This chapter reviews the reasons behind the adherence challenge, its implications for access to the new therapies, and the current state of research on adherence to antiretroviral medications for HIV/AIDS among injection drug users. A theoretical perspective drawn from studies of chronic illness in medical anthropology—social course—is introduced, followed by a case study showing how the social course perspective can shed light on the dynamics of adherence among drug users over time. Clinical and policy implications of research on the social course of adherence are discussed briefly at the end of the chapter.

**Key words:** Social course, medical anthropology, adherence, access, combination antiretroviral therapy, HIV/AIDS

## **INTRODUCTION**

Recent advances in the clinical management of human immunodeficiency virus (HIV) infection—the availability of viral load monitoring and new, highly potent medications—have occasioned what has been termed a “Lazarus syndrome” (Goodman 1997; Leland 1996) in persons with HIV/AIDS (acquired immunodeficiency syndrome). Accumulating evidence that new drugs significantly prolong the lives of patients (Deeks et al. 1997; Hammer et al. 1997; Hogg et al. 1998a; Palella et al. 1998) is turning AIDS into a disease that one lives with rather than dies from. If

present trends continue, we may witness a complete transformation of AIDS from a “death sentence” to a “chronic illness.”

In light of rapidly expanding options for therapy, in 1996 the U.S. Department of Health and Human Services and the Henry J. Kaiser Family Foundation convened the Panel of Clinical Practices for the Treatment of HIV. The panel was charged with the development of guidelines for the clinical management of HIV-infected persons. Its report (Report of the NIH Panel . . . 1998) includes both principles of therapy and guidelines for the use of antiretroviral medications and is referred to herein as the “National Institutes of Health (NIH) Guidelines.” This set of recommendations takes its place alongside the guidelines of the International AIDS Society (Carpenter et al. 1996). The new guidelines endorse aggressive combination antiretroviral therapy (ART) for all persons with advanced or symptomatic HIV disease. Initiation of therapy in HIV-positive individuals who are asymptomatic involves weighing multiple considerations, including willingness to accept treatment, degree of current immunodeficiency, risk of disease progression, and likelihood of adherence.

The standard of care for aggressive initial treatment is simultaneous, combination ART consisting of two nucleoside reverse transcriptase inhibitors (NRTIs) and a protease inhibitor (PI).<sup>1</sup> NRTIs stop HIV from reproducing by mimicking part of the virus’ genetic material.<sup>2</sup> PIs stop replication by interfering with the protease enzyme, which divides HIV proteins into the tiny particles needed to construct new viruses.<sup>3</sup> Suppression of replication to levels undetectable by sensitive plasma HIV ribonucleic acid (RNA) assays is considered the goal of therapy.

Combination ART marks a critical step forward in the search for an effective AIDS treatment; yet for patients, the drugs have major drawbacks. Side effects such as nausea, diarrhea, and neuropathy can be severe enough to substantially impede daily functioning and erode quality of life. Medication regimens are complicated: multiple daily dosings at regular, defined intervals; avoidance of food for specified periods before and after dosing; intake of large quantities of water; and, not insignificantly, combining ART with other medications. Some pills have unpleasant textures and tastes, and their large size makes them difficult to swallow. Frequent blood drawings are required to monitor levels of both medications and indicators of HIV infection.

## **ADHERENCE TO COMBINATION ANTIRETROVIRAL THERAPY**

Perhaps the most daunting challenge for those attempting combination ART (and those who care for them) is the challenge of adherence. Strict adherence to prescribed regimens is essential, not only to derive benefit from the drugs but also to avoid the development of resistance to them. Good adherence from the beginning is particularly important, since the greatest potential for benefit occurs with the initial trial of anti-HIV therapy (Guidelines . . . 1998). Unfortunately, however, no clear and precise definition of "strict adherence" exists.

Moreover, judging from the research literature, there is little agreement on the meaning of adherence, appropriate indicators, or how these should be measured. Some investigators have operationalized adherence as patient self-report (Samet et al. 1992; Weidle et al. 1998). However, what is being reported (e.g., frequency of doses missed in the past week, most recent dose taken, doses consumed the previous day or previous month, etc.), to whom the reports are made (e.g., peer support group, physician), and how (e.g., prospectively, retrospectively) varies widely. Some measures of "compliance" compute percentages of clinic appointments kept (or missed) (Samuels et al. 1990; Turner et al. 1998). Other measurements focus on biological markers, such as medication levels in the blood (Samuels et al. 1990; Smith and Page 1996) or elevation in mean corpuscular volume of red blood cells, a side effect of long-term treatment with zidovudine (AZT) (Broers et al. 1994; Ferrando et al. 1996). Still others use indicators of virologic response to therapy (e.g., HIV RNA, CD4+ lymphocyte counts) to measure adherence (Mannheimer et al. 1998). Each of these approaches is incomplete, addressing a single dimension of adherence with differing degrees of accuracy. One of the more comprehensive definitions of adherence suggests that dose, timing, diet, followup appointments, and dedication to the regimen are all necessary for good adherence (Hirschhorn 1998).

The development of resistance to new antiretroviral medications poses grave threats to both individuals with HIV/AIDS and the general public. For the infected person, resistance means the end of a particular drug's effectiveness in combating HIV and its elimination from the armamentarium of possible treatments. The seriousness of this situation is compounded by the fact that only 11 new, "potent"

antiretroviral drugs are currently approved and available for general clinical use:

- zidovudine [AZT] (Retrovir)
- didanosine [ddI] (Videx)
- zalcitabine [ddC] (Hivid)
- stavudine [d4T] (Zerit)
- lamivudine [3TC] (Epivir)
- saquinavir (Invirase)
- ritonavir (Norvir)
- indinavir (Crixivan)
- nelfinavir (Viracept)
- nevirapine (Viramune)
- delavirdine (Rescriptor)

Each one that loses efficacy significantly narrows the range of remaining treatment options for a given individual. Sooner or later, the patient confronts the prospect of “running out of meds.”

Persons receiving treatment for HIV/AIDS are nonetheless thought to be infectious, and since the introduction of the combination therapies, researchers have waited and watched, hypothesizing that HIV strains resistant to the new drugs would—or would not—prove transmissible. Evidence of transmission of drug-resistant strains of HIV would represent an enormous setback in the struggle against AIDS, even as it heralded a major public health hazard, for it would mean that forms of HIV for which no effective treatments exist could be spread in the community (Hecht et al. 1998).

This double-barreled danger of resistance—the danger to the individual and to the public health—inspired one observer to dub adherence the “Achilles’ heel” of potent ART (Friedland 1997). As such, adherence has emerged as the pivotal point in a set of controversies over who should and should not and who is and is not receiving combination HIV ART.

Clinicians who treat persons infected with HIV routinely must make judgments as to when to recommend initiation of combination ART. Likelihood of adherence is one of several considerations to be weighed in arriving at these judgments. Where all signs point to success, the medications may be prescribed with reasonable confidence. When there are questions or doubts about the ability to adhere, however, a moral dilemma arises. Should treatment be

postponed? This could be in the patient's best interests, given that to begin therapy and fail may mean losing the opportunity for maximal therapeutic effect or, worse, the development of resistance that precludes future benefit from the drugs. In deferring life-sustaining treatment, however, clinicians may be accused of breaching patient autonomy, exercising medical paternalism, and forcing those desiring access to the medications to seek them from illegitimate sources and consume them without professional supervision. On the other hand, in not deferring treatment where the capacity to adhere is in question, it may be argued that clinicians are abrogating their responsibility to the public health (Bayer and Stryker 1997).

## ACCESS TO COMBINATION ANTIRETROVIRAL THERAPY: SOCIAL DIMENSIONS

The NIH Guidelines for the use of combination ART state explicitly that "no patient should automatically be excluded from consideration for antiretroviral therapy simply because he or she exhibits a behavior or other characteristic judged by some to lend itself to noncompliance" (Guidelines . . . 1998, p. 48). Yet accumulating evidence suggests that access to the new therapies varies systematically by social group. Accounts in the research literature and the popular press indicate that women (Bangsberg et al. 1998; Nakashima et al. 1998a; Strathdee et al. 1998), blacks (Nakashima et al. 1998b), homeless persons (Bangsberg et al. 1997, 1998; Sontag and Richardson 1997; Waldman 1997), and injection drug users (IDUs) (Bangsberg et al. 1998; Moore et al. 1998; Nakashima et al. 1998a) tend to be underrepresented among persons using combination ART for HIV/AIDS. Among IDUs, persons who are defined as active users or are not enrolled in drug treatment are less likely to be receiving these medications than individuals with histories of drug use who are thought to be abstinent at the time therapy is considered (Celentano et al. 1998; Strathdee et al. 1998).

Part of the explanation for the underrepresentation of IDUs among persons using combination ART surely lies in the challenges inherent in treating this population in general. Because they tend to have multiple medical and psychiatric conditions and because they are most often poor, the health care needs of IDUs are complicated. This makes them "difficult patients" whom busy clinicians, however dedicated and well-meaning, may inadvertently find themselves trying to avoid. Layered atop this basic problem is the impression,

seemingly quite widespread among health professionals, that the "unstable lifestyles" of IDUs prevent them from being able to adhere to therapeutic regimens, especially complex and demanding ones. The facts that, depending on the circumstances, these individuals may lack permanent housing, reverse typical sleep patterns, abstain from eating for long periods while using drugs, and otherwise lead irregular lives are taken as evidence that they lack the capacity to take medications as prescribed. This conviction appears to have contributed to the exclusion of IDUs from clinical trials (Smith and Page 1996) and may well underlie recent assertions that postponement of combination ART with a PI in the context of active injection drug use is justifiable while the drug use is being addressed (Celentano et al. 1998; Sherer 1998).

## **RESEARCH ON ADHERENCE TO ANTIRETROVIRAL MEDICATIONS FOR HIV/AIDS IN DRUG USERS**

A few researchers have set out to examine empirically adherence to ART among drug users. A small cluster of studies investigating adherence to AZT therapy in IDUs provides evidence that (1) this population does not, in general, differ significantly from other high-risk groups and (2) rates of adherence among active users, while perhaps less favorable than those of abstainers, can be relatively good (Broers et al. 1994; Samuels et al. 1990; Smith and Page 1996).

Findings from new research on adherence and illicit drug use, much of which focuses specifically on combination ART, were presented at the 12th World AIDS Conference. Some studies compared IDUs with persons who do not use illicit drugs; others compared current with former IDUs. Still others focused exclusively on either active drug users or persons with histories of illicit drug use. The results of these studies appear to be mixed, with some investigators reporting no or "very modest" relationships between drug use and adherence (Carrieri et al. 1998; Hogg et al. 1998b; Mannheimer et al. 1998; Turner et al. 1998; Weidle et al. 1998) and others reporting a negative association between adherence and illicit drug use (Hirschhorn et al. 1998; Ohmit et al. 1998; Stone et al. 1998; Williams et al. 1998). It seems clear that, with respect to combination ART, the adherence capabilities of IDUs—particularly active IDUs—have yet to be satisfactorily assessed and described.

The practice of postponing combination ART for active drug users raises a number of critical questions. Does the decision to postpone vary by drug of choice (e.g., heroin versus MDMA [3,4-methylenedioxymethamphetamine, or “ecstasy”] or marijuana) or mode of ingestion (e.g., injecting or smoking versus sniffing)? Does alcohol abuse or dependence constitute grounds for postponement? Does the postponing clinician have a responsibility to help the patient obtain drug treatment, given the long waiting times for access to publicly funded facilities? What are valid indicators of abstinence? What if an individual is unable to access treatment and fails to find another way to stop using drugs? How long should a postponement decision stand before being reevaluated? Are there circumstances under which active IDUs can successfully adhere? A policy of deferring treatment with combination ART for active IDUs may prove morally indefensible in the long run, if it develops into the indefinite withholding of life-extending therapy on the basis of unexamined assumptions about the meaning of belonging to a given social group.<sup>4</sup>

## A SOCIAL COURSE PERSPECTIVE ON CHRONIC ILLNESS

In the 1980s Kleinman (1982, 1986) introduced the term “sociosomatic” as a way of conveying the idea that bodily distress can be socially induced. Sociosomatic refers to a relationship in which symptoms result from, and often symbolize, painful social experiences such as political violence, geographic dislocation, and sexual or physical abuse. Thus, sociosomatic relations are a way of explaining symptoms. The argument that symptoms develop in sociosomatic relations has also given rise to an analogous claim: that illness has a *social course*. A succession of definitions of social course has been offered by Kleinman and colleagues, each one less narrowly symptom-focused than the last (Hicks et al. 1998; Kleinman et al. 1995; Ware and Kleinman 1992). The most recent designates the “life lived with illness,” rather than the bodily complaint, as the object of analysis (Ware 1998).

This latest definition of social course provides the basis for a conceptual model of social course that is based on longitudinal research on illness course in chronic fatigue syndrome. In this model, marginalizing social processes are opposed by individual acts of resistance to move ill persons back and forth along a spectrum—closer to and farther from the perceived centers of their social worlds. Marginalizing

processes include role constriction—the increasing inability of chronically ill persons to fulfill social functions—and delegitimation—systematic disconfirmation of the subjective experience of being ill. Acts of resistance are strategies designed to preserve everyday life as it existed prior to illness onset or to reconstitute it in ways that allow for continued participation in social life. In this formulation, social course consists of successive, bidirectional movements over time, along a “continuum of marginality,” by persons living lives with chronic illness (Ware, in press).

A social course perspective has a number of distinguishing features. It highlights *social process* in contrast to behavior, defining as the unit of analysis the reciprocal influences of social context on the experience of individuals and individual agency on social context. It is *longitudinal*, not in the sense of examining cross-sectional “slices” of phenomena at specified intervals, but acknowledging that experience is continuous and attempting to trace patterns of continuity and change in experience over time. Finally, a social course perspective concerns itself with *meaning*, offering detailed definitions and descriptions of experiences and concepts from the points of view of multiple constituencies.

### **ETHNOGRAPHIC PILOT STUDY OF THE SOCIAL COURSE OF ADHERENCE TO COMBINATION ANTIRETROVIRAL THERAPY IN HIV/AIDS**

The notion of social course and its elaboration in previous research have provided the starting point for an ethnographic pilot study of the social course of adherence to combination ART in HIV/AIDS. The study focuses particularly, although not exclusively, on users of illicit drugs.

Study participants are 10 individuals who are HIV positive or have a diagnosis of AIDS. Approximately equal numbers of men ( $N=4$ ) and women ( $N=6$ ) are included. The group is racially and ethnically diverse, consisting of five African Americans, four whites, and one Latino. Eight of the participants have histories of illicit drug use; three of these are former IDUs. At least four are currently using illicit drugs, principally cocaine. All are receiving services at a clinic that provides comprehensive care for persons with HIV/AIDS and were referred to the study by health professionals there.

Data collection consists of a series of four open-ended interviews with each participant. With permission, interviews are audiotaped and transcribed. Data are being collected using an iterative process, whereby the transcript of each interview is analyzed to generate questions for the next. The iterative process in data collection and analysis is a basic methodological tool in ethnographic research.

Although the interviews are being constructed out of an iterative process, particular topics are also explored in every encounter with each study participant. These are topics considered central to the study of social course in HIV/AIDS in general and to the focus of the present project in particular; for example, adherence to medications, illicit drug use, and health status. Data are being rendered as interpreted case studies, one of which is presented in some detail below.

### **Case Study: Bill Jones**

This case focuses on the development of “readiness” for ART. Readiness—whether for medical treatment, drug treatment, or physical or psychiatric rehabilitation—typically masquerades as a discrete point in time, long prepared for but fragile and fleeting. In the case of drug treatment, for example, readiness is construed as a “moment” of receptiveness on the part of the client that must be seized immediately or risk being lost. In casting it as part of the social course of adherence in HIV/AIDS therapy, the intent is to disclose readiness as social process, developing continuously and extending not only up to but also beyond initiation of treatment. From a social course perspective, the clinical question to be asked is not only “when” to begin therapy but also “what” readiness course an individual has previously followed and “how” to help him or her construct a successful course of readiness for the future.

Twenty years ago Bill Jones, a 50-year-old white man, was married, working at a steady job, and living in a small New England city. In 1981 he had a brief extramarital affair, as a result of which his wife ended their relationship. Two years later he was working as the superintendent of a small apartment building, in exchange for rent. One day a friend asked if she could use his apartment to shoot heroin, and he agreed. Later she moved in and brought others home to use drugs. Soon Bill himself was using—first sniffing, then, very shortly, injecting cocaine. A period of injecting “speedball” (cocaine and heroin) followed. Then, finally, Bill began injecting

heroin—"constantly," as he puts it. He lost his job as a result of his drug involvement and has not worked since.

Bill insists he scrupulously avoided dirty needles—except, by accident, once. He traces his HIV infection to this single "slip-up," which occurred approximately 3 weeks after he began injecting drugs. About a year later, in 1984, he was admitted to the hospital because he was "having a problem with his arm." In the course of treatment for that problem, he was told he was HIV positive. His HIV status was not addressed, however, and he received no treatment for it. For about 10 years after learning he was infected with HIV, Bill had no interest in treatment. None of his friends were being treated. There was no cure for AIDS. "Why take medications when I'm going to die anyway?" he reasoned.

As he recounts, Bill was completely immersed in the world of injection drug use during this 10-year period. While living in an abandoned building with other users, his activities consisted of getting high when he had drugs and being sick when he did not. When he was sick, the search for drugs to relieve withdrawal symptoms was all-consuming. This roller-coaster existence of alternating highs and lows went on for years until one day, when everyone was told to leave the house. Others dispersed in all directions; Bill went home to live with his mother. Although he continued to use drugs, this move turned out to be highly significant in several respects.

First, it changed the configuration of Bill's interpersonal world. No longer surrounded exclusively by other users, he was forced to confront nonusing family members who cared about him: his mother, pained at watching her son struggle with withdrawal sickness; his son, who gazed at him uncomprehendingly and not a little fearfully. Fed up with having his mother witness repeated withdrawals, Bill eventually sought medical help. In the process of being evaluated for drug treatment, his HIV status was reconfirmed, and a protocol of antiretroviral medications recommended. However, he did not begin taking anti-HIV drugs at that time, believing that "too many years had passed" since infection for him to benefit from medication, but he did seek access to a methadone maintenance program.

Seeking access meant placing weekly phone calls to the program staff to reiterate his commitment to entering treatment until an opening

became available. In Bill's case, this took 8 weeks. He succeeded in making most of the calls, even though he was still using drugs. Once, feeling sick and still waiting to be accepted into treatment, he borrowed money from his mother to purchase drugs. It felt like hitting an all-time low. The guilt and shame that ensued renewed his flagging determination to keep knocking at the door of the methadone clinic:

That day, I got the drugs, and I felt better. But then I thought, "my *mother* gave me that money! . . . She's on SSI [Supplemental Security Income]. She doesn't have any money!" And for her to take \$20 out of her bill money so that she didn't see her son sick like that . . . I felt like a heel. I said, "God, you gotta help me, please." And I stuck to it. I kept calling the clinic.

While waiting to be accepted into the drug treatment program, Bill continued to be followed at the outpatient medical clinic where he had initially sought help. He missed many appointments due to withdrawal sickness and drug use, but when he was there, he read posted notices and other materials promoting adherence to HIV medications. After a while, he later reports, he began to think, "Well, if I take my meds, maybe I'll be OK!"

Then he began methadone maintenance, and as he puts it, "everything got put together." Because he was on methadone and off heroin, Bill no longer had to spend his days procuring drugs. He began keeping more medical appointments. He joined a support group for persons living with HIV. As he experienced what it was like to have regular contact with professionals and peers who cared about his health, Bill began to care more as well. One day he said to himself, "Let's see if I can beat this thing!" and began taking his medication in earnest.

Bill was now highly motivated—committed to deriving the greatest possible benefit from his medications. Yet from the point of view of health care professionals, his adherence was incomplete. Bill's drug regimen, as he reports it, consisted of one tablet of lamivudine (3TC)/AZT (Combivir) twice daily. But he took only one tablet once a day.

Bill's decision not to follow adherence instructions completely was deliberate and based on two distinct and explicit lines of reasoning. First, he was "doing well," having achieved an undetectable viral load

while taking only one pill a day. As time passed, he expected to need more and more of the drug to maintain his present status. By taking what appeared to be a minimally effective dose, he preserved the option of increasing it when the necessity arose. He would even have the drugs already available, since he was “saving” the pills he did not consume for future use.

His second line of reasoning was essentially a critique of standardized dosing. Bill believed the effectiveness of medications varied with the individual and that, therefore, not everyone necessarily needed to take the same amount. He was skeptical about the origins of dosing recommendations. Bill chose not to disclose his “disobedience,” fearing that if his providers knew what he was doing, they would lose interest in his care. Despite his general policy of nondisclosure, Bill decided to reveal to his physician that he was taking only half the prescribed dose. It might be clinically significant, he reflected—evidence that the standard dose is excessive and should be reduced or an indication that others can also achieve good results with smaller amounts of the drug. When his doctor greeted the news with “disappointment,” however, Bill felt immediately that he had made a mistake and tried promptly to rectify it by promising to take two pills a day from then on. The doctor, in turn, tried to explain to him why consuming the prescribed dosage was critical.

As good as his word, Bill immediately doubled his dose of medication and continued to take that amount for 2 weeks. He had not really understood the doctor’s explanation of the importance of taking the whole dose, however. Determined to take the best possible action to preserve his health, he decided to consult others. His brother’s advice echoed Bill’s own view. Thus reinforced, Bill’s original logic prevailed, and he returned to his “incomplete” pattern of adherence, which he has followed ever since.

Currently, Bill’s viral load is undetectable. He does not have a diagnosis of AIDS. Since beginning methadone maintenance, he reports complete abstinence from illicit drugs.

**Discussion.** Readiness, for Bill, started slowly, with a long period of indifference to HIV medications fueled by an attitude of fatalism: “Why bother? There’s no cure. I’m going to die anyway.” It was 10 years before he abandoned indifference in favor of incipient optimism about medical treatment for HIV. A “last straw” experience served as the catalyst for the shift: One too many

withdrawal episodes witnessed by his mother inspired Bill to seek help for his drug addiction. As a result, he was catapulted into movement on two fronts: a gradually increasing receptiveness to the idea of HIV therapy and a persistent “banging on the door” of drug treatment.

After weeks of fruitless attempts to access a treatment facility, Bill’s determination flagged. A painful emotional experience rekindled it—an experience of intense self-denigration and shame over having taken money from his mother to buy drugs.

Readiness accelerated rapidly for Bill once he began drug treatment. Liberated from the endless cycle of using and seeking drugs, he had time and energy to devote to his health. He listened to his doctors and nurses, learned from others taking HIV drugs, and finally came to a point of engagement with therapy. “Let’s see if I can beat this thing,” he declared, making a commitment in that moment to survival through the use of medications to fight HIV.

How a trajectory—a *course*—of readiness began to take shape can be seen by examining Bill’s case history. Some of its *ingredients* are periods of change and no change; events that fall into a pattern (accumulating embarrassment at having his mother see him withdraw, culminating in a last straw that moved him to seek methadone treatment); “critical incidents,” whose meanings jumpstart subsequent development (as when his shame at having taken money from his mother to buy drugs reinforced his determination to get clean); and turning points that mark changes in course.

A number of attributes of readiness course are also evident in Bill’s experience. *Temporality* is highlighted by the fact that the trajectory of change has momentum, beginning with the decision to seek drug treatment and accelerating once treatment began. Bill’s case also reveals something of the *complexity* of readiness course. It is not a single series of discrete phases, unfolding neatly in sequence. Rather it spills onto multiple, simultaneous “tracks,” such as when Bill’s quest for drug treatment and his initial engagement with the idea of treatment for HIV, both part of readiness, take place at the same time. The courses of drug use and of HIV/AIDS illness also intersect. It was because he was sick from withdrawal, for example, that Bill sought medical help and was offered HIV therapy. Drug treatment made the commitment to adherence seem not only possible but worthwhile.

Complexity also exists in the different types of change that occur. At least three types are discernible in Bill's readiness course. At the emotional level, he moved away from fatalism and hopelessness toward hope. At the behavioral level, he sought and gained access to drug treatment, stopped using injection drugs, and started taking steps to care for himself. At the level of interpersonal relations, he changed social worlds, moving out of the realm of drug users and surrounding himself with nonusers: family, health professionals, other drug users in recovery, and persons living with and taking medications for AIDS. New physical environments were part of the change in social world. No longer a squatter in an abandoned building, Bill now had a home and places to go besides the street.

In retrospect, we can see how this change of social world mediated other aspects of his readiness course. It was seeing himself, sick from withdrawal, reflected in the eyes of his mother that precipitated his first step toward recovery. Sitting in the waiting room of the medical clinic and reading wall posters and HIV literature prompted his first serious consideration of beginning HIV therapy. Through the caring of his family, doctors, drug rehabilitation counselors, and others, he learned to value himself. Also, he learned to care for himself by following the instructions and examples of health professionals and peers. As one form of social influence, social mediation reveals part of the meaning of *social course*.

Through Bill's management of his treatment protocol, we glimpse both *how* patient definitions of adherence can differ from those of clinicians and *why*. His understanding of how his medications work contrasts sharply with biomedical knowledge. It is an understanding grounded in an identifiable conceptual model. Bill subscribes to a "habituation theory" of HIV medications, a theory clearly informed by his years of experience as a heroin user. The theory predicts that, as with heroin, the body will develop a tolerance for antiretroviral drugs over time. As a result, larger and larger doses will be needed to produce the desired effect. Given this theory, one rational course of action is to take a minimally effective dose. This approach anticipates the habituation effect and allows for an increase in dosage when the necessity arises. In taking half the recommended amount of Combivir, in his view, Bill is practicing good adherence as part of a committed effort to promote his health.

Bill's decision not to disclose his pattern of adherence is inspired by the same motive. Recall that at this stage in his readiness course, he is

doing everything possible to, as he put it, “beat this thing.” To accomplish this, he needs not just perfunctory cooperation but also full and energetic support from his health care providers. Previous experience suggests that the best way to ensure that support is to “follow orders.” However, because of his habituation theory of HIV medications, Bill believes he cannot follow orders completely without jeopardizing his health. So he hides his adherence practices. Again, for him, this is a *health-promoting* decision.

Clinicians can contribute to improved adherence with combination ART by acknowledging that patients may have theories about HIV medications that depart significantly from their own. Insofar as possible, clinicians should elicit and engage these theories and be prepared to educate clients by offering new and better ones. Bill’s case makes clear the importance, for patients, of having a theory to define and guide rational efforts at improving health. Clinicians can fulfill this need and support individuals in their efforts to stay healthy by supplying them with *good theories* about their medications and making sure these theories are understood.

Bill’s case also speaks to the presumption that active users of illicit drugs lead unstable lives that prevent them from successfully adhering to complicated medical regimens. Bill was not homeless when he began the readiness process by seeking help for his drug addiction. Nor was he skipping meals and sleeping days. The instability in his life revolved around episodes of withdrawal sickness and his efforts to “treat” them by using illicit drugs. Despite this, he was able to keep some of his medical appointments and maintain regular contact, at specified intervals, with a drug treatment facility. The dangers of failing to explore degrees and varieties of instability and their implications for adherence are clearly evident in Bill’s case.

Since his readiness increased markedly after beginning drug treatment, some may wish to invoke Bill’s experience as evidence supporting postponement of combination ART for active drug users. This particular case was selected for its usefulness in illustrating the social course of readiness. Examples of successful adherence by active drug users also appear in the data.

### **John Smith**

One such example is John Smith, a 45-year-old African-American man and self-described heroin addict since the age of 15. He began drug therapy for HIV/AIDS in 1997. His current regimen consists of ddI (Videx, an NRTI), d4T (Zerit, an NRTI), and nevirapine (Viramune, a nonnucleoside reverse transcriptase inhibitor [NNRTI]).<sup>5</sup> He carefully times his doses to match prescribed intervals and plans his meals to conform to the restrictions on food intake required for adherence to ddI. Most days, he also uses cocaine.

John was slow to accept medication for HIV because, as he put it, “when you take it, you’re making a commitment. You’re gonna be taking it for the rest of your life.” When he finally made the commitment to therapy, he knew he would stick with it, having thought the decision through so carefully and having waited so long. He did not, however, make a commitment to stop using illicit drugs. He explains: “I didn’t want to take this stuff [HIV medications] in the beginning. So when I made that commitment, I knew I was going to have to go along with it. But I didn’t make a commitment to stop doing drugs, too! I made a commitment to try to not do as much as I was doing.”

## **CONCLUSION**

The NIH Guidelines repeatedly emphasize the importance of making decisions to initiate or postpone combination ART on an individual basis and avoiding assumptions “that any specific group of persons are unable to adhere” (Report of the NIH Panel . . . 1998, p. 13). They also stipulate that treatment decisions should be arrived at jointly by patients and their health care providers. The guidelines largely stop short, however, of specifying indicators to guide the decision-making process. Bill’s case and others examined as part of the research reported here suggest several such indicators: (1) level of individual motivation and commitment to succeeding at adherence; (2) past performance in following other types of medication regimens, particularly those requiring multiple daily dosings and dosings at specified times; (3) existing social supports, including not only health care and other service providers but also members of the larger social network; (4) availability of technical or other material aids to adherence—for example, pill boxes (with or without timers), beepers, and programmable wristwatches; (5) personal strategies for achieving adherence, developed by the patient to reflect his or her particular

daily routines, individual attributes, and so forth; and (6) patient understanding, not only of the requirements of adherence but also the reasons behind them (e.g., the mechanisms of action of new antiretroviral drugs and rationales for taking them in combination).

An individualized approach to treatment decision making is enhanced by taking *social course* into account. A social course perspective casts adherence as process rather than behavior. This means that “readiness,” for example, occurs not as an all-or-nothing phenomenon or a discrete point in time, but rather as a sequence of co-occurring, overlapping experiences that increase and decrease and speed up and slow down, extending not only up to but also beyond the initiation of treatment. The implication is not only *malleability*—readiness can be molded, shaped, continuously improved—but also *continuousness*. Readiness is ongoing and as such should be consistently monitored as part of support for adherence.

Particular meanings of “social influence” and “social context” come to the fore from this perspective as well. Bill Jones’ case clearly shows that social factors *mediate*, not just elaborate, explain, or even steer the course of readiness. They intervene as catalysts, turning points, and accumulations of events that “tip the balance” in one direction or another. A social course framework replaces a focus on causal relationships with more sophisticated ways of thinking about mechanisms of social influence.

A social course perspective can shed considerable light on the dynamics of adherence among IDUs, including active users, as the analysis of Bill’s experience clearly demonstrates. Careful dissection and examination of the ingredients of adherence (such as readiness), their relationships, and the patterns they describe over time is the first step toward answering questions about the ability of active IDUs to follow complicated medical regimens and the most effective ways to support them in their efforts. *In what ways* does active drug use impede adherence? Does the capacity to adhere differ according to the user’s drug of choice? What explains why some IDUs can use drugs and maintain acceptable adherence at the same time while others cannot? Is it valid to assume that “instability” interferes with adherence for IDUs? What forms of instability? Under what circumstances? Is instability ever irrelevant? Answers to these and related questions will help health care providers and their drug-using patients resist social stereotypes and make informed, individualized decisions about the initiation of combination ART for HIV disease.

## NOTES

1. In this chapter, however, the term refers to combinations in which protease inhibitors are and are not included.
2. NRTIs currently available are zidovudine (AZT), ddI (Videx), d4T (Zerit), 3TC (Epivir), ddC (Hivid), and zidovudine/lamivudine (Combivir).
3. Four PIs are currently approved for clinical use: indinavir (Crixivan), nelfinavir (Viracept), ritonavir (Norvir), and saquinavir (Invirase).
4. Patricia Case, Sc.D., contributed to the points articulated in this paragraph.
5. A nonnucleoside reverse transcriptase inhibitor is a type of drug that prevents reproduction of HIV by binding to the reverse transcriptase enzyme of the virus. NNRTIs currently available are nevirapine (Viramune) and delavirdine (Rescriptor).

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# **Chapter 9. Ethics, Ethnography, Drug Use, and AIDS: Dilemmas and Standards in Federally Funded Research**

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## **ABSTRACT**

Since the Second World War, there has been a significant increase in researcher attention to the issue of ethical conduct during the research process. While much of the focus in the ethics discourse has been on issues encountered in biomedical research, and on the establishment of a broad foundation of ethical standards for this field, intensive discussion of ethical issues has occurred in the social sciences as well. Professional associations in all of the social sciences have developed and disseminated ethical guidelines. However, these may be of only limited assistance to certain types of social research. Ethnographers involved in the study of drug use and HIV risk continually encounter a number of unique ethical challenges because of (1) the naturalistic and participatory nature of their research method, (2) the illegal and potentially lethal nature of the behaviors under examination, and (3) the fact that much of this research is supported by public funding. This chapter reports on a special workshop sponsored by the AIDS Advisory Committee of the Society for Applied Anthropology that was designed to examine the impact of these three factors on the ethnography of drug use and HIV risk and to establish a set of ethical standards to guide this research.

Key words: Ethics, HIV and drug use research, ethnography, Federal research funding

## **BACKGROUND**

The acquired immunodeficiency syndrome (AIDS) pandemic sparked a significant increase in research on illicit drug users in the United States and abroad. Much of this research, which is designed to expand the understanding of risk behavior among drug users and develop effective prevention efforts, is supported by Federal research institutes, including the National Institute on Drug Abuse (NIDA) and the Centers for Disease Control and Prevention. Ethnography has emerged as a central methodology in this research initiative (Baer et al. 1997; Lambert et al. 1995). Thus far, this research has produced a number of important social benefits, including the identification of little recognized routes of human immunodeficiency virus (HIV) transmission, alternative strategies for intervention, a fuller understanding of the initiation of risk behavior in social context, and avenues for culturally sensitive intervention. It also has raised significant ethical questions.

Although the history of public focus on the establishment of ethical standards for research with human subjects dates to the Nuremberg War Crimes Trials and the Nuremberg Code, ethnographers often confront unique ethical challenges because of the special nature of their research methodology (Marshall 1991). As a result, anthropological professional organizations, such as the American Anthropological Association (AAA) and the Society for Applied Anthropology (SfAA), as well as related professional associations from other disciplines, have established principles for ethical ethnographic research. These codes of ethical conduct may offer general guidelines for ethnographic research, but they generally do not address specific issues that arise in the study of the behaviors of those who use illicit drugs, issues that warrant careful consideration and deliberation (Clatts, *in press*). These issues, in large measure, arise because the ethnography of the intertwined epidemics of drug use and AIDS put ethnographers directly into situations in which illegal and risky behaviors regularly occur. Given the dramatic increase in ethnographic drug and AIDS research, there is a window of opportunity to be proactive in establishing standards to guide this research.

In this light, on January 10-11, 1998, an ad hoc committee of anthropologists and other researchers concerned with ethical issues in the ethnographic study of users of illicit drugs gathered together at the Hispanic Health Council in Hartford, CT, to participate in the

Workshop on Ethical Issues in Illicit Drug User Research: Toward the Establishment of Ethical Guidelines. This committee was established by the AIDS Advisory Committee of the SfAA, with encouragement from Dr. Richard Needle, Chief, Community Research Branch, NIDA, to achieve three goals: (1) review the special set of ethical issues that arise in federally funded research on illicit drug users, (2) review the wider range of ethical issues that arise in the ethnographic study of illicit drug users, and (3) draft principles for broader dissemination and ratification to guide this research. This chapter addresses the first of these objectives within the context of the wider set of issues involved in the ethnographic study of users of illicit drugs in the era of AIDS.

## ETHICS AND RESEARCH

Differences in values, expectations, and experience contribute to ethical dilemmas when various stakeholders in research (e.g., community members, researchers, sponsors) have disagreements or misperceptions about what should occur as part of the research.

Three philosophically based principles are viewed as central to ethical research with human subjects:

1. Respect for persons. This principle accepts that people have the capacity, and must be accorded the right, to act as autonomous moral agents, including voluntary, noncoerced participation in research that is based on the provision of informed consent.
2. Beneficence/nonmaleficence. This principle maintains that researchers have an obligation to pay close attention to the health and well-being of human subjects and to use research to maximize human well-being.
3. Distributive justice. This principle holds that standards of equality and fairness must be followed in determining who benefits and who bears the burdens of research (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1978).

These three principles provide the components of an overarching framework for establishing specific guidelines for ethnographic research generally and for ethnographic research with illicit drug users specifically, but they do not fully address many of the

specific issues that arise in ethnographic research, particularly in cross-cultural settings. Consequently, ethically sound ethnographic research must be guided by at least two additional ethical considerations:

- **Sociocultural sensitivity.** Focused concern with individual autonomy, free will, and self-determination has its source in Western cultural traditions, which are not universal concepts. Researchers working in non-Western cultural settings (including certain subgroups physically located in the West) must be highly sensitive to cultural beliefs and practices that may affect appropriate standards for the conduct of ethical research. Informed consent, for example, requires an understanding of the social roles, networks, and structures that may be pertinent to truly informed and approved consent for research participation. Insensitivity to cultural tradition is in violation of the principle of respect, which must be extended beyond individuals to groups and their cultural values, practices, and traditions. The narrow use of Western ethical standards without sensitivity to local norms may be construed as an act of ethical imperialism.
- **Sociohistorical contextualization.** The history of humanity over the past 10,000 years is in part one of conquest, domination, and exploitation. The cultural memories of oppressed populations are long and influence contemporary behavior and attitudes. Ethical research depends on an awareness of the specific sociohistorical sensitivities of the communities of research interest. Research in the African-American community, for example, risks ethical violation if it is blind to community sensitivity to the social meanings inherent in the Tuskegee syphilis study (i.e., researchers must strictly avoid even the appearance of withholding state-of-the-art treatment and provide, in advance, full community explanations of research plans). Similarly, research in Latino communities should be guided by awareness of sterilization campaigns and widespread pharmaceutical testing.

In addition, the nature of ethnography raises several special issues in the establishment of ethical conduct in research. Ethnographic research is distinctive because of its:

- Location of performance (in the social and geographic domains of the community under study).

- Context of realization, which is interwoven with everyday and sometimes private, intimate, or highly emotionally charged activities of study participants.
- Investigative goals (to grasp the sometimes private, insiders' understanding and world view, to understand their behavior in social context, to assess the interconnections among parts of the research community's sociocultural world, and to link this world with the wider transnational social sphere).
- Methods of data collection (including, in addition to the use of quantitative research tools, participation in the day-to-day activities of members of the community under study, as well as informal interviewing, direct observation of behavior in context, and the examination of multiple domains, including linguistics, social organization, and technology).
- Level of personal commitment. Ethnographers often do not go to work per se; they live on the job, and their work involves a full immersion in the lives of their research participants; hence, the personal lives of ethnographers are not, by design, separate from those of research participants.
- Style of presentation (a holistic narrative description of behaviors, events, and social meanings, as well as underlying patterns and associations).

One consequence of this approach to understanding is that ethnographers often spend a lot of time with research participants and commonly develop close personal relationships with at least some of them (e.g., marriage in the field is not an uncommon occurrence among ethnographers). Indeed, from the research subject's perspective, the ethnographer as a person may be of far greater significance than the ethnographer as a researcher (a role that the subject may not understand well). Whereas in many lines of inquiry researcher responsibility falls primarily within the specific context of the risks or burdens generated by the research project, in ethnography the boundaries between research activities and other arenas of study participants' lives may be blurred. As a result, the ethnographer "contract" with study participants may be broader than it is in clinical, epidemiological, or other kinds of research. These features of ethnography create special challenges for ethical conduct.

In response, to ensure adherence to ethical standards, in 1971 AAA adopted a set of Principles of Professional Responsibility (revised in 1990). These principles indicate researcher responsibility to:

1. The people whose lives and cultures anthropologists study—by avoiding deception, ensuring voluntary consent, protecting confidentiality, avoiding exploitation, and avoiding doing harm
2. The general public—by communicating honestly, considering the consequences of communication, and using knowledge gained through research for the public good
3. The discipline—by protecting the discipline's reputation, avoiding plagiarism, justly treating colleagues, and showing respect
4. Students and trainees—by treating them fairly, offering appropriate assistance and guidance, recognizing their contributions to work, and avoiding taking advantage
5. Employers, clients, and sponsors—by being honest
6. Governments—by being candid and setting ethical limits on acceptable assignments

These principles constitute useful discipline-sensitive applications of the more general set of overarching research guidelines noted above—respect for persons, beneficence/nonmaleficence, and justice—as well as offering a statement of specific responsibilities to various stakeholders in the ethnographic research process. Similarly, the SfAA and the National Association of Practicing Anthropologists have developed statements of professional and ethical responsibility. These statements identify obligations to the various constituencies of the research process that are similar to those found in the AAA document. Together, these documents address many of the issues confronted by ethnographers in their effort to conduct ethical research, but they do not address the special ethical dilemmas presented by the contemporary ethnographic study of drug users, including unique issues that arise when the research in question is supported by a federally funded research grant.

## FEDERALLY FUNDED RESEARCH WITH DRUG USERS

Although many methodologies have been employed in the social scientific study of users of illicit drugs, moral decision making may be more complex in the ethnographic investigation of this population than in many other kinds of research because of (1) the intimacy between researchers and study participants, which is inherent in participant observation research; (2) the fullness of researcher awareness of study participants' behaviors, health status, and attitudes; and (3) the length of the research endeavor—often more than a year and sometimes involving multiple revisits over time. Specific ethical issues that must be addressed under such circumstances include:

- Knowledge of illegal behavior by study participants
- Knowledge of dangerous or unhealthy behavior by study participants (including behaviors that may harm others)
- Responsibilities (in some settings, such as along the U.S.-Mexico border region) that arise from working with individuals, such as illegal immigrants, whose presence in the country is punishable by law
- Responsibilities that arise from working with highly vulnerable populations, including minorities and traditionally oppressed populations, as well as with individuals such as drug dealers and commercial sex workers whose behaviors make them subject to social opprobrium
- Responsibilities that arise from working with populations that differ culturally from the dominant population
- Ambiguous or blurred personal/professional boundaries and the potential for intimacy between the researcher and study participants
- Knowledge of highly intimate and confidential information about study participants, including information that, if disclosed, could cause harm to subjects, damage their social relationships, or put them at considerable risk

- Study participants' requests and demands for researcher involvement in problematic (including illegal) behavior
- Study participants' pressure on the researcher to redirect research project resources in ways not intended in the study design
- Responsibilities that arise because of the frequent association between drug use and violence
- Responsibilities that arise because study participants may suffer from mental health problems that limit their ability to act in their best self-interest

While adhering to the ethical standards derived from the principles of respect for persons, beneficence, and justice, ethnographers studying drug users must confront these issues without losing sight of their obligations to various constituencies (e.g., study participants, sponsors, employers, colleagues, the wider community) and their responsibility to take reasonable safety precautions to protect themselves in potentially risky situations.

Because federally funded research is supported by public funds, it is subject to additional considerations. These include issues of legality; responsibilities to employers, colleagues, and the discipline; and the increased possibility of public, governmental, and mass media scrutiny. Although it is generally accepted that the researcher's most fundamental ethical responsibility is to the people who volunteer as participants in research projects, there is also a strong researcher responsibility to protect sponsors from inappropriate condemnation, recognizing that research findings may produce criticism of sponsors because of sponsors' failure to fulfill their obligations. In other words, federally funded research may produce results that lead to criticism of the Federal Government (e.g., results showing that on any given day only 15 percent of injection drug users [IDUs] are in drug treatment), but researchers are ethically obligated in accepting Federal research support to ensure that inappropriate actions of the researcher during investigations are not the source of sponsor condemnation. Researchers also have responsibilities to the institutions that employ them and to their colleagues who are engaged in parallel research. Researchers must not assume that they are the only ones who will suffer for their problematic behaviors. Balancing all of these obligations is no mean feat. Unfortunately, these issues have not commonly been subjects of collegial discussion.

In particular, the ethical issues that arise in publicly funded research with individuals engaged in illegal and risky behavior have received little attention. The remainder of this chapter, consequently, addresses the issue of obligations to Federal sponsors in the ethnographic study of users of illicit drugs in light of the concepts and special circumstances outlined in the previous sections.

### **Confronting Ethical Issues in the Ethnographic Study of Users of Illicit Drugs**

The January 1998 workshop addressed a number of potentially problematic behaviors and ethical dilemmas in federally funded research with illicit drug users. All of these dilemmas have been experienced by fieldworkers, sometimes with painful consequences, including researcher participation in:

- Sharing drugs with study participants
- Procuring (through buying, trading, etc.) drugs for study participants
- Holding or transporting drugs for study participants
- Transporting study participants to acquire drugs
- Allowing study participants to use drugs in the researcher's car, home, or other property (personal or belonging to one's employer)
- Giving or lending study money to study participants to buy drugs
- Acquiring syringes or other drug paraphernalia to give to study participants
- Holding syringes, other drug paraphernalia, or weapons for study participants
- Assisting study participants in avoiding arrest for illegal activities (e.g., being a lookout during drug use/acquisition activities)
- Having sex with study participants
- Hearing study participants threaten to harm someone

- Being offered potentially stolen property by study participants (for sale or in the form of a gift)
- Observing a significant risk behavior by study participants (e.g., syringe sharing by an HIV-discordant couple)

As this list demonstrates, in the contemporary study of illicit drug users, there are numerous, often difficult, and not self-evident decisions that researchers may have to make. The points raised and judgments reached by workshop participants during discussion of a limited number of these issues are addressed below. In some instances, points made with reference to one issue were deemed applicable to one or more additional issues, resulting in more circumscribed discussion. A thorough analysis of each of the potential ethical issues mentioned is beyond the scope of this chapter.

***Sharing Drugs With Study Participants.*** The first issue that must be addressed in assessing this matter entails answering the question, Why might ethnographers even consider using drugs with participants during the study of illicit drug use behavior?

Ethnographic research is founded on the methodological strategy of participant observation. Ethnographers are expected, within reason, to become involved broadly in the lives of the people under study to better understand the fine-grained details of their way of life, the interconnections that underlie group social patterns, and the insider's experience and view of social reality. Ethnography, in short, assumes the importance of "walking in the study participants' shoes" as a means of most fully comprehending their social world (within the bounds of what is possible by a researcher who, in most instances, must remain an outsider to the group under study). Moreover, ethnographers recognize the importance of developing rapport with their study participants and understand that rapport is facilitated by participation in key activities of the community under study. Failure to participate in certain activities may cause offense or alarm. For example, Partridge (1973), during his study of a hippie community in Florida, was offered heroin by a drug dealer who was a member of the community. He declined to purchase the drug.

After an initial invitation and my subsequent refusal to join this network I was seldom engaged in conversation by any of these persons. A few days after my refusal of the invitation (to buy heroin) I passed a known dealer and user on the street and he

refused to speak. Not all heroin dealers were this distant, but I collected little data from them. This was unfortunate . . . .

Also, in oppressed communities whose way of life is denigrated by the dominant society, participation may be experienced as an expression of respect and acceptance not commonly accorded to members of the majority group. Finally, study participants may express the expectation that the researcher share drugs with them as proof that she or he is not an agent of social control. Do these factors justify drug use with study participants?

At the simplest level, it might be argued that researchers should not use illicit drugs as part of research. However, the legality of a particular behavior does not constitute an adequate basis for ethical decision making. During the period of slavery in the United States, returning a runaway slave was a legal obligation. Whether it was an ethical behavior is a completely separate issue. There is a long tradition of civil disobedience as a means of protesting unjust laws. Cultural heroes, like Dr. Martin Luther King, Jr., sometimes achieve widespread social and ultimately legal support through the violation of unjust laws. In short, it may be ethical in some circumstances to be in violation of the law. This is not to say, of course, that punishments—including loss of research funding and imprisonment—in and of themselves may not be adequate reason to avoid illegal behavior during research; for most researchers, they certainly would be, but not for all. Some may feel uncertain and ambivalent about appropriate behavior in certain research settings. Lack of explicit professional standards of conduct regarding drug use in the field may enhance researcher uncertainty about appropriate behavior.

Although it has not been widely publicized, ethnographers in various research settings (usually outside the United States and not supported by Federal funding) have, on occasion, participated in drug use with their research participants. Most often this has occurred in settings where drug use is a traditional and ubiquitous practice or part of a religious ritual in the society or community under study. Slotkin, for example, an anthropologist who studied Native Americans, was also a member and officer of the Native American Church, which uses peyote (*Lophophora williamsii*), a hallucinogenic cactus, as a sacrament. Slotkin published several articles and a book on Native American peyotism based on participant observation, including peyote consumption (e.g., Slotkin 1955). Similarly, Furst and Myerhoff, two U.S. anthropologists, accompanied and studied a

group of Huichol Indians in Mexico on a sacred pilgrimage that included the gathering and ritual consumption of peyote (Myerhoff 1976). Myerhoff refers to the experience, in which both she and Furst consumed peyote, as one of “collective ecstasy” (Myerhoff 1976, p. 157). Participation in drug use by researchers also has occurred in less ritualized and traditional settings. One of the earliest such accounts was De Quincey’s (1995) *Confessions of an English Opium Eater*, originally published in 1822, which was based on the author’s participant observation study of several socially eminent drug users. Without doubt, the most famous case of a field researcher reporting the use of drugs as part of the research process is found in the work of Carlos Castaneda, which began while he was an anthropology student at the University of California, Los Angeles. In *The Teachings of Don Juan: A Yaqui Way of Knowledge* (Castaneda 1968), and in a subsequent series of volumes, Castaneda recounted the use of several drugs—including peyote, jimsonweed (*Datura inoxia*), and a mushroom (possibly *Psilocybe mexicana*)—as part of his participant observation study/apprenticeship with a Mexican Yaqui Indian shaman. In the foreword to Castaneda’s first book, Goldschmidt, a prominent American anthropologist, wrote:

Anthropology has taught us that the world is differently defined in different places . . . We know something of the shape of these other worlds from the logic of native languages and from myths and ceremonies, as recorded by anthropologists. Don Juan has shown us glimpses of the world of a Yaqui sorcerer, and because we see it under the influence of hallucinogenic substances, we apprehend it with a reality that is utterly different from those other sources. This is the special virtue of this work (Goldschmidt 1968, p. vii).

As this statement suggests, ethnographers sometimes defend drug use in certain research settings as an appropriate expression of participant observation research (Harner 1973). In ethnographic terms, drug consumption as part of the study of a drug-using group allows the researcher to transcend the divide between etic (the understanding gained by an outside observer) and emic (the understanding gained by an inside participant).

Although workshop participants acknowledged ethnographer motivations for drug use as part of the study of a group in which drug consumption is a socially approved behavior, they concluded that Federal Government funding of research on drug use that is the end-

phase of the international illicit drug trade calls into question the ethical appropriateness of sharing drugs with research participants. Several reasons for this conclusion were offered. First, there is potential for harm to be done to research participants who, while engaged in drug use, may suffer an overdose or other health or legal complication when sharing a drug with a researcher. Contributing to the potential for these negative outcomes in any way is a violation of the obligation of beneficence—do no harm—toward study participants. Second, by engaging openly in illegal activities with study participants, researchers become vulnerable to blackmail or other coercion (e.g., by individuals already involved in illegal activities who, under the pressure of their drug dependency, may resort to desperate measures to obtain drugs). Third, researchers who suffer from a drug dependency should not, on ethical grounds, use research on drug use as a covert justification for their own continued drug consumption.

Workshop participants also identified other significant reasons for not using drugs during federally funded research. The first of these stems directly from the illegality of drug use but has additional moral aspects concerning the issue of honesty. As part of the assurances given to the funder in federally funded grants, the grant recipient must agree to maintain a drug-free workplace. Having given this assurance, the principal investigator, the funded institution, and by extension, staff members hired on the project have a moral obligation to avoid drug use during the performance of work activities. In this regard, it should be stressed that in ethnography, the office and “the field” (wherever drug users are observed, engaged in conversation, and interviewed) constitute the workplace. Other ethical considerations that argue strongly against using drugs with research participants include the following:

- Harm done to science, due to impairment of the ethnographer’s ability to conduct high-quality research while under the influence of drugs
- Harm done to the researcher’s credibility with those study participants who would be hesitant to be open and honest with a researcher who was consuming drugs (e.g., How believable would assurances of confidentiality be from a researcher involved in drug use?)

- Harm done to colleagues, whose research funding may be put in jeopardy because of the damage done to the reputation of ethnography in the eyes of the funder
- Harm done to funders, whose reputation may be damaged in the eyes of the public or Congress
- Harm done to the funded institution (e.g., university, research institute, community organization), whose future funding may be put at risk because of violation of the drug-free workplace assurance
- Harm done to local communities that benefit from programs implemented as part of or as a result of drug-related research (e.g., prevention and treatment programs)

Many of these issues stem from the *principle of good reputation*. This principle is described in the AAA Principles of Professional Responsibility as follows: “Anthropologists bear responsibility for the good reputation of the discipline and its practitioners . . . They must not behave in ways that jeopardize either their own or others’ future research or professional employment.” Using illicit drugs with research informants during federally funded research, it could reasonably be argued, could lead to a loss of good reputation for ethnography in the eyes of Federal funders and in the eyes of Congress, which allocates funding to Federal research institutes and other institutions. For example, were an ethnographer to use drugs with a research informant and were this to become public knowledge (e.g., through a newspaper article), Congress could conceivably impose restrictions on all federally funded ethnographic research, which might jeopardize that researcher’s or others’ future research and professional employment. Whatever one’s personal values, on the basis of the principle of good reputation (for oneself, one’s employer, one’s funder, and for ethnographic research), workshop members argued that it is unethical to use drugs in federally funded research. Ethnographers must recognize that, unlike in the past when most ethnography was done by researchers working alone in the field, many ethnographers now work for institutions, often as members of research teams, and they are funded by other institutions. As a result, they have ethical obligations to all of these entities, as well as to the people they study. In summary, workshop participants identified a number of clear reasons why drug use by researchers as part of or

during a federally funded research project would be a violation of ethnographic research ethics.

**Procuring Drugs for Study Participants.** Why might ethnographers consider procuring drugs for research participants during the study of drug use behavior? Ethnographers often develop personal relationships with their key research participants, some that may be lifelong and emotionally intense. In this situation, when the research subject is a dependent drug user and begins to suffer the potentially painful symptoms of drug withdrawal, the researcher may feel a human obligation to end the suffering by acquiring drugs and providing them to the subject. The structure of the research relationship can help generate this sense of obligation because the researcher may harbor guilt that she or he is receiving information that could have a long-lasting benefit for the researcher's career while providing little in return that benefits the study participants.

In examining this situation, workshop participants noted that procuring drugs—through buying, trading, or other means—is an illegal activity. The researcher is put at risk for legal action, and research participants may suffer the consequences of the researcher's illegal activity (e.g., they may be arrested while in possession of drugs procured by the researcher). Most of the other ethical issues raised with regard to the use of drugs with research participants also apply to the question of procuring drugs, although in some cases, procurement may be seen as an even greater ethical violation of appropriate research standards than using drugs with research informants. By actually procuring drugs (the chemical composition of which the researcher often cannot guarantee), the researcher may be putting research participants directly in harm's way through overdose or exposure to tainted substances. Similarly, it is likely that even greater harm may be done to employers, funders, and colleagues through the act of procuring drugs for others than in the researcher's personal use of drugs, because one is assisting other people in violating laws and social standards. Furthermore, through the act of procurement, the researcher is vulnerable to coercion from drug distributors, who may not be as close to the researcher as other participants in the drug scene. For all of these reasons, workshop participants concluded that drug procurement for research participants by researchers as part of or during a federally funded research project would be a violation of ethnographic research ethics.

**Holding or Transporting Drugs for Study Participants.** Why might ethnographers consider holding or transporting drugs for research participants during the study of drug use behavior? Again, the answer stems from the nature of ethnography and the types of relationships that develop between researchers and the people they are studying. Because a research subject may spend long hours patiently answering an ethnographer's endless questions, introduce the ethnographer to other informants, and assist the ethnographer in gaining access to events, locations, and social networks not ordinarily accessible to the ethnographer, a sense of obligation may develop. The ethnographer consciously or unconsciously may begin to seek ways to repay the informant for his or her time and effort. At the same time, the informant may begin to ask for favors or repayment in some form. If a research subject has prior arrests and being caught with drugs could result in a lengthy sentence, he or she may ask the ethnographer to hold or transport drugs for protection from a jail term. Workshop participants concluded that it would be unethical for the researcher to comply. Such an act directly fosters a study participant's involvement in drug use. If this use leads to an overdose or other consequence for the participant or others, the researcher would bear some of the responsibility. Furthermore, agreement to hold or transport drugs may be the first step to increasingly more problematic requests from study participants. Finally, all of the issues discussed above with reference to the principle of good reputation apply to the issue of holding or transporting drugs during a research project.

**Holding Syringes, Other Drug Paraphernalia, or Weapons for Study Participants.** Why might a researcher hold or carry drug paraphernalia or even weapons for study participants? Although drug users are not inclined to let others take control of their "works," in cases where arrest for possession of drug paraphernalia or weapons could result in protracted imprisonment for an individual with prior offenses (e.g., see Koester 1994), this person may attempt to recruit the researcher (who may have no prior arrests) for this task. Researcher reasons for considering (or even offering) to hold or transport study participants' drug paraphernalia or weapons could include the desire to protect a key informant from imprisonment, the need to demonstrate one's sincerity and authenticity, or the need to reciprocate informant assistance as noted above. However, in the view of workshop participants, items that are part of drug abuse or violence or that could be involved in enhancing AIDS risk should not be held or distributed by ethnographers; this does not apply, of

course, to materials like condoms or even sterile cookers, which researchers may carry and distribute for the explicit purpose of preventing harm. However, an exception to this general guideline must be noted; for example, a researcher may rightly feel a moral responsibility to convince a study participant to relinquish a weapon as a means of preventing that individual from using it to do harm. Thus, while it is possible to establish general principles of ethical conduct in research, each situation is unique and calls for constant ethical evaluation and decision making by the researcher (see Marshall, this volume).

***Acquiring Syringes or Other Drug Paraphernalia To Give to Research Participants.*** If multiperson reuse (“sharing”) of syringes is one of the primary routes by which HIV and other blood-borne pathogens are spread among drug users, is it not ethically appropriate for researchers, when possible, to give new, sterile syringes to injection-drug-using study participants? A number of local and Federal legal issues are involved in this decision. Researchers who study IDUs should be aware of local laws that pertain to possession or distribution of syringes without a prescription. In addition, they should be aware of local interventions (e.g., syringe exchange programs) and other factors that affect access to sterile syringes (e.g., pharmacy sale of over-the-counter syringes). With this information, researchers may be able to direct drug users to legal sources of sterile syringes.

If such sources are not available, researchers with access to sterile syringes may decide to distribute them to out-of-treatment IDUs as an AIDS prevention strategy with demonstrated efficacy. Local laws may prohibit this as an illegal act, which may constitute a situation of conflict between the researcher’s legal and ethical responsibilities. Researchers must consider the consequences of going against that law—for themselves and their families, their employers, and the people they are studying. In some instances, researchers decide to support unsanctioned syringe exchange and suffer the legal and other consequences of their actions (Bluthenthal et al. 1997).

Researchers who receive Federal funding must also be aware of the array of barriers to using Federal dollars to directly support syringe exchange or distribution. The U.S. Congress has enacted a series of statutes, including the Comprehensive Alcohol Abuse, Drug Abuse, and Mental Health Amendments Act of 1988, the Health Omnibus Programs Extension of 1988, the Ryan White Comprehensive AIDS

Resources Emergency Act of 1990, and the Departments of Labor, Health and Human Services, and Education and Related Agencies appropriation acts of 1990 and 1991, that contain language specifically prohibiting or restricting the use of Federal dollars to support syringe exchange. These laws have been interpreted by the U.S. General Accounting Office as allowing the U.S. Department of Health and Human Services (DHHS) to authorize demonstration research projects on syringe exchange efficacy and outcomes. However, although this has allowed the funding of syringe exchange evaluation, it has not resulted in the direct funding of syringe exchange services, and will not, unless the Surgeon General of the United States determines that such programs are effective in preventing the spread of HIV and do not encourage the use of illicit drugs (U.S. Congress 1992). Although there have been efforts to prompt such a ruling by the Surgeon General and although in 1998 the DHHS Secretary publicly acknowledged the effectiveness of syringe exchange in limiting the spread of HIV among IDUs, the use of Federal funds in support of syringe exchange continues to be prohibited (Singer 1997; Vlahov and Junge 1998). As a result, federally funded researchers (and research staff members) who participate directly in needle exchange may face loss of research funding or other consequences, however ethical their actions may be in terms of preventing the harm of disease transmission.

***Having Sex With Study Participants.*** Researchers rarely report having sex during the research process. Given the nature of ethnographic research and the way it traditionally has been conducted (by a lone researcher who spends many months in a foreign setting immersed in the lives of people who are not part of their usual social networks), this may not be because such behavior never occurs, but because it is a particularly touchy subject. One of the few ethnographic accounts that provides some detail about the relationships involved and their impact on the fieldworker was written pseudonymously (Cesara 1992). On the whole, Wengle (1988, p. 25) concludes that “the vast majority of anthropologists remain celibate while in the field.” Bolton (1992), one of the few ethnographers who openly (and in his own name) admits not only to having sex with study participants but also to using his sexual encounters in the field as the subject of his research (which focused on the willingness of gay men in Belgium to initiate risky sexual practices), maintains that fear of ridicule and condemnation has forced researchers to avoid public acknowledgment of having sex with informants (and of benefiting from the insights into the group under study that such intimate interaction allows).

In explanation of his approach and its justification, Bolton, who received no Federal funding (nor expected to ever receive it), argues the following:

No deception was involved in any phase of the research, and the behaviors engaged in were consonant with those that are normative within the community being studied; moreover, my research objectives were subordinate to my participation as a member, albeit temporary, of the community I was studying. In practice that means that I never engaged in any behavior that I would not have engaged in had my research objectives been different . . . The most basic responsibility of the field-worker is to protect informants from negative consequence. In this research, the anonymity of informants was guaranteed . . . Some anthropologists may interpret the use of . . . [my] research methodology as a violation of the responsibility . . . [to maintain] the “good reputation of the discipline.” . . . [However in the midst of a major health crisis,] the reputation of the discipline can only be enhanced by significant contributions to the solution of societal problems (Bolton 1992, p. 136).

While Bolton makes some excellent points, some researchers have argued that, in many contexts, having sex with study participants is coercive and that the potential for manipulation (in either direction) is extremely high. Having sex with study participants in situations where it is not coercive is still unprofessional, it has been argued, because it changes the nature of the relationship with informants and interferes with the collection of defensible data not subject to lingering doubts concerning the biased nature of ethnographic research findings. Moreover, having sex with study participants may put the researcher at risk for all of the problems and complications (e.g., interference with fieldwork, jealousy, accusations of infidelity, blackmail, rejection, gossip) that can accompany any sexual relationship. The objectivity of the researcher under these conditions would be subject to question in the eyes of many nonethnographic researchers. Also, attitudes about sex and intimacy are socially constructed and variable. Interactions that may have one meaning in the researcher’s home community may have different implications in a research setting. Finally, the development of sexual relations between a researcher and study participants creates the potential opportunity for the spread of sexually transmitted diseases. Although a researcher—like anyone else—could limit this potential through the use of condoms and other safe sex procedures,

researchers—like everyone else—can have lapses in their adherence to protective measures for a variety of reasons.

Consequently, workshop participants concluded that it was highly inappropriate for researchers studying drug users to have sex with study participants. Federal support of such research makes this behavior all the more questionable given researcher responsibility to funders. Although Bolton's study produced important insights about HIV risk among gay men, it did not demonstrate that such insights could not have been achieved through more conventional methodologies.

***Observing a Significant Risk Behavior by Study Participants (e.g., Syringe Sharing by an HIV-Discordant Couple).*** One of the most difficult ethical dilemmas that drug researchers confront is the observation of behaviors that are capable of transmitting HIV from infected to noninfected individuals. Multiperson reuse of syringes and other drug paraphernalia (“sharing”), which is responsible for most HIV infection among heterosexuals in developed nations, for example, continues to be observed and described by ethnographers in many locations (Inciardi and Page 1991; Koester and Hoffer 1994). When researchers are aware of the HIV status of infected individuals and observe them engage in HIV risk behaviors with others who are not infected, do they have an ethical responsibility to intervene in some fashion? In other words, when there is a direct conflict between confidentiality and HIV prevention, which ethical responsibility has the higher priority?

Settings and circumstances in which conflict between responsibility for maintaining participant confidentiality and responsibility to act with beneficence vary greatly. In some settings, it may be possible for researchers to provide a discrete warning of risk without breaching confidentiality. HIV prevention messages can be provided, for example, without reference to the serostatus of participants. In addition, it may be possible to talk directly with the HIV-infected individual about ways of protecting others from infection. With reference to transmission risk, the reactions of individuals after learning that they are HIV positive vary along a continuum, from concern about not transmitting the virus to others to disregard for protecting others. Openness to prevention messages will vary depending on where an individual falls on this continuum.

In considering the option of breaking confidentiality, researchers must remember that (1) not every risky act results in HIV transmission, (2) violation of confidentiality may lead to additional risk if either the seropositive or the seronegative participant becomes angry, (3) awareness that a drug associate is seropositive often does not dissuade another drug user from sharing drug paraphernalia, and (4) the benefits expected to be produced by the research project may be lost if members of the target population come to believe that their confidentiality cannot be protected. For these reasons, workshop members concluded that explicitly breaching confidentiality to prevent a potential risk event should be avoided in most instances unless the seronegative individual is not in a position to make autonomous decisions about her or his behavior (e.g., being a minor).

## CONCLUSION

At all times, researchers should be guided by the principle of avoiding harm and, when possible, of acting to lower the potential for harm. Unfortunately, this requires considerable balance and judgment about behaviors that have unforeseen consequences. As a result, it is incumbent on researchers to consider potential ethical issues prior to initiating research and to be alert and responsive to ethical dilemmas when they occur in the course of research. Guidelines such as those presented here can help in this process; however, each situation is unique, and special conditions may shift the balance regarding whether a particular behavior causes or avoids harm (or causes more harm than good). Organizers of the Workshop on Ethical Issues in Illicit Drug User Research: Toward the Establishment of Ethical Guidelines were especially concerned about the impact of Federal research funding on ethical decision making in drug research. It was the opinion of workshop members that the source of funding is important because of the contractual agreements made by researchers when they accept money from a funder. Although researchers must not avoid investigations capable of producing findings that challenge the status quo (e.g., by exposing inequality, maltreatment, or other injustice), they have an obligation to funders, employers, colleagues, and the communities that they study to be fair, uphold their agreements, and avoid causing needless harm to others.

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# **Chapter 10. An Approach to Ethical Decision Making in Ethnographic Research on HIV Prevention and Drug Use**

*Patricia Loomis Marshall*

## **ABSTRACT**

Investigators engaged in policy-related studies involving drug users and the prevention of HIV are challenged by ethical problems in the implementation of their research. This chapter introduces a guide for resolving ethical dilemmas in ethnographic HIV prevention and drug abuse research. Drawing on models of ethical decision making in clinical care, this guide to moral reasoning emphasizes thoughtful and deliberate reflection on the nature of the ethical problem encountered, including individual and social values surrounding the dilemma, and the identification of persons and communities vulnerable to harm. The ethical decision making guide outlines a series of questions that assist investigators in determining strategies for resolving conflicts that maximize respect for everyone involved in the ethical dilemma.

**Key words:** Ethical decision making, ethnographic research, HIV and drug use

## **INTRODUCTION**

Ethical dilemmas are often encountered in the implementation of anthropological investigations of drug use and human immunodeficiency virus (HIV) prevention (e.g., Clatts, *in press*; Singer, Marshall, Trotter et al., *this volume*). Myriad factors contribute to the difficult ethical challenges that arise in ethnographic fieldwork with individuals involved in illicit drug use. In some cases, ethical problems are associated with the anthropological methods employed in the research (Bernard 1994). For example, the use of participant observation in ethnographic studies may result in ethical issues concerning informed consent or the protection of participant confidentiality. In other cases, ethical dilemmas are unique to investigations of drug use and HIV prevention, including, for

example, requests to procure, hold, or transport drugs or drug paraphernalia. Although anthropologists are increasingly involved in federally and privately funded research on drug use and HIV prevention, little attention has been given to the moral dilemmas that ethnographers confront in implementing their investigations, nor has there been discussion of approaches for resolving dilemmas when they occur.

Drawing on strategies for ethical decision making in medical care (e.g., Thomasma 1978; Thomasma and Marshall 1995), the following model suggests a preliminary approach to resolving ethical conflicts in ethnographic research on HIV prevention and drug use. This approach to moral reasoning in ethnographic research is not meant to be a formulaic algorithm for solving the perplexing issues encountered in fieldwork. Rather, it is intended as a guide for ethical decision making for anthropologists and others confronted with complicated ethical problems in the course of implementing research on drug use and HIV prevention. It offers a set of questions that provide the researcher with a direction for purposeful reflection on the thorny problems that sometimes occur in carrying out investigations. The model provides a framework for thoughtful and systematic consideration of the full range of issues surrounding moral dilemmas in ethnographic research with drug users. In addition, its use encourages ethnographers to be reflective in thinking about the nature of moral crises in the field and the consequences of decisions made in response to the dilemmas they encounter.

## **ETHICAL WORKUP GUIDE FOR ETHNOGRAPHIC RESEARCH**

### **Step 1. Describe the Problem**

In the initial phase of decision making, information regarding the research dilemma, including details concerning the nature of the study, the research design, the study sponsor, the participants, and the anticipated outcomes of the research, should be outlined.

### **Step 2. Determine the Relevant Values**

The researcher should consider the cultural and social values represented in the dilemma. In this process, the researcher should describe the relevant values of research participants, their relatives and friends (if pertinent), the investigators, the sponsors, and the local community. Societal values regarding scientific investigations

and the need to gather information on the particular topic also should be determined.

### **Step 3. Identify the Primary Ethical Dilemma**

The researcher must determine the nature of the principal value conflicts and establish the primary conflict in his or her opinion. In making this determination, the researcher should consider whose values are threatened, that is, who are the most vulnerable to harm. This process of reflection facilitates the identification of the key issue involved in the ethical dilemma.

### **Step 4. Determine Possible Strategies for Resolving the Ethical Dilemma**

The researcher should identify a range of possible courses of action that might be taken to resolve the dilemma. The researcher must consider the risks and benefits associated with each of the strategies, including which values are protected and which values are threatened by particular solutions.

### **Step 5. Identify a Course of Action**

The researcher must identify the strategy that maximizes respect for relevant individual and group values encountered in the dilemma. The vulnerability of research subjects should always be an important consideration in determining the course of action. In choosing a strategy, the researcher might ask the following questions: Does this solution mesh with my personal values and goals? Am I willing to discuss the solution with others, including my professional colleagues? Do I want people to know what I am doing? Can I justify the course of action morally and scientifically—to myself, to study participants in the research, and to the sponsors of the research?

### **Step 6. Defend the Course of Action**

A course of action that can be defended personally and professionally should be chosen. In this process, the researcher might reflect on the meaning of professional and personal integrity. The researcher should consider the resolution of the ethical dilemma in terms of the values at risk and the values protected. The following questions might be considered: Should the final decision be determined by a single ethical justification or one dominant social or personal value, or should as many values as possible be protected? What are the

benefits and harms associated with the decision I have made? How can I justify my decision?

## CONCLUSION

Anthropologists and others engaged in ethnographic investigations on HIV prevention and drug use will continue to encounter perplexing ethical dilemmas in the course of their research. Ethical principles governing anthropological research are not unique to this discipline; respect for persons, beneficence, and justice are vital concerns for any scientist. The way in which these principles are expressed in the implementation and design of a study depends, in part, on constraints imposed by the specific context. In this regard, anthropologists are likely to encounter more obstacles than other social scientists, especially those engaged in policy-related investigations such as ethnographic studies involving drug users and the prevention of HIV transmission. There are no easy solutions when moral conundrums occur. Indeed, the very definition of what constitutes an ethical dilemma is problematic—what is viewed as morally troubling by one investigator may not be considered difficult by another researcher. The framework for decision making outlined here represents an attempt to clarify the questions to be considered in resolving ethical dilemmas.

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# **Chapter 11. The Ethnography of Street Drug Use Before AIDS: A Historical Review**

*Merrill Singer*

## **ABSTRACT**

This chapter examines the recent expansion in drug use ethnography ushered in by the AIDS epidemic in terms of the long prior history of ethnographic studies of drug use behavior. The objective of the chapter is to draw attention to useful information on drug use and health risk patterns found in the pre-AIDS ethnographic literature on street drug users. More recent literature on illicit drug use—written by ethnographers who entered this domain of research only with the advent of the AIDS epidemic—often appears to overlook this older literature as if it held no relevance to HIV prevention research. Two pre-AIDS eras of research are examined: (1) the long history of naturalistic observations on drug use by travelers, colonial officers, writers, and others that were made prior to the emergence of modern ethnographic training and systematic research methodology and (2) the formal pre-AIDS ethnographic literature on the behaviors, views, and experiences of street drug users written by anthropologists and sociologists (as well as autobiographical literature by participants in the street drug scene). The paradigms and approaches that characterize each of these eras are explored to reveal the ways in which research findings are strongly shaped by the kinds of questions researchers ask and the ways in which they think about the issues of research concerns.

**Key words:** History of drug ethnography, research paradigms, lessons for AIDS research, changing drug use patterns

## **INTRODUCTION**

The acquired immunodeficiency syndrome (AIDS) epidemic, and the consequential role illicit drug consumption has played in the transmission of the human immunodeficiency virus (HIV) in several regions of the world, sparked a radical upsurge in the ethnographic study of drug users and what have come to be labeled their “risk

behaviors.” On reviewing the first decade of HIV transmission and drug use studies, Page concluded that many of the researchers involved in this work were unfamiliar with prior field research on drug use:

Their first accounts of the risk of infection linked to injecting behavior therefore had a distant view of intravenous drug use that took into account few of the possible variations in self-injection behavior already pointed out in the literature. As time passed and the early AIDS investigators became more familiar with intravenous drug use, their analyses of injection behavior became somewhat more astute . . . (Page 1990, pp. 478-479).

Page’s lament draws attention to the way the AIDS epidemic demarcates two somewhat separate periods in the ethnographic study of drug users: studies conducted before and since the beginning of “the time of AIDS” (Herdt and Lindenbaum 1992). Close examination of the long and uneven period before the AIDS epidemic suggests a further parsing into observational studies of drug use carried out before and after the rise of the modern era of systematic ethnographic research. In short, there have been three phases in the ethnography (and quasi-ethnography) of drug use and three largely independent qualitative drug use literatures: (1) premodern studies carried out by interested amateur observers, (2) modern studies conducted by trained field researchers and ethnographers who viewed their work as objective social science, and (3) postmodern studies conducted by professional ethnographers whose intellectual and emotional worlds had been severely disrupted by the twin forces of the AIDS epidemic and the postmodern challenge to scientific authority. Although all typologies have their limitations (in the real world, phenomena refuse to be restrained by carefully crafted categories), observational studies on drug use fall roughly into these three time periods. The objective of this chapter is to review the seminal fieldwork-based reports and publications on drug use and other relevant literature from the two pre-AIDS eras noted above. The intention is to help provide a historical foundation for contemporary drug use and AIDS risk ethnography as a corrective to the repeated loss and rediscovery of valuable information and insights decried by Page (1990).

## **SHIFTING PARADIGMS AND ABANDONED LITERATURE**

In part, the tendency in the ethnography of drug use to lose touch with the work done in previous eras is inherent in the nature of scientific inquiry. Scientific investigation is conditioned by two simple but powerful truths: Paradigms matter, and paradigms shift. The critical importance of these points was established through the seminal work of Kuhn (1996), who showed that each arena of scientific inquiry is shaped by one or more established conceptions about the basic nature of the subject matter under study. These fundamental conceptions, which he called paradigms, are the taken-for-granted foundations on which scientists know their field, generate specific questions, conduct research projects, and interpret findings. Consequently, day-to-day work within a scientific field, what Kuhn (1996) terms “normal science,” is strongly influenced by the reigning paradigms shared by fellow scientists. As a result, as Gould (1998, p. 72) argues, “Utterly unbiased observation must rank as a primary myth and shibboleth of science, for we can only see what fits into our mental space, and all description includes interpretation as well as sensory reporting.” Over time, as the social world changes in the wake of historical circumstance (such as the appearance of AIDS), the concepts that guide understanding within a field of scientific inquiry shift. When this occurs, researchers come to see the world differently, ask new questions, and employ alternative strategies to acquire answers.

Thus, each of the phases in the ethnography of drug use has been characterized by differing perspectives. Assuming that they hold little relevance to contemporary concerns is one of the key reasons that researchers often do not become deeply familiar with the literatures of prior eras. This chapter proceeds on a different assumption, namely, that the ethnographic study is strengthened by grounding current research in historical social and theoretical contexts. Although the primary focus of this chapter is on “street drug use” (Stephens and Levine 1991), it is argued that this social phenomenon is best understood in light of the long history of field studies of human interaction with psychoactive chemicals (see Baer et al. 1997).

## **ALMOST ETHNOGRAPHY: PREMODERN FIELD STUDIES OF DRUG USE**

The use of drugs to alter states of consciousness or mood is ancient and widespread. The earliest known use of opium, for example, dates

to 6,000 to 7,000 years ago among the ancient Sumerians of the Fertile Crescent (Lindesmith 1968). Hesiod's description of the ancient Mediterranean city of Mekone ("Poppy Town") provides an early glimpse of the cultivation of opium poppy plants (Kritikos and Papdaki 1967). Another early written account of possible drug use is found in the work of Greek historian Herodotus, who described the practice of sweat bathing in marijuana fumes among the Scythians, a 5th-century nomadic people of central Asia. In a modern global study, Fort (1969) found drug use on every continent, although drugs of most common use and methods of consumption varied.

According to Feldman and Aldrich (1990), the first quasi-ethnographic account of drug use was penned by Christopher Columbus and Friar Ramón Pané, the man assigned by Columbus to record native customs. Based on conversations with Taino Indians on the Caribbean island of Hispaniola in 1496, Pané described their experience of taking a drug they called cohoba, which was eventually discovered to be a hallucinogenic extract (containing dimethyltryptamine and bufotenine among other alkaloids) of the bean of the tree *Anadenanthera peregrina* (Altschul 1972; Schultes 1977a). Pané's account of indigenous use of a hallucinogenic snuff—one of at least 100 types of snuffs that so far have been identified among New World peoples (Schultes 1977b)—dates the beginning of observational drug studies to more than 500 years ago. He also provided a description of tobacco use among the Tainos, a drug they smoked in huge cigars to comfort the limbs, induce sleep, and lessen weariness. Not surprisingly, like other accounts of the premodern era, Pané's description was not based on the systematic assembly, comparison, and validity checking of fine-grained data that characterize ethnography as a social scientific research method. However, Pané did base his description on firsthand, on-the-ground observation and informal interviewing of participants, hallmarks of the ethnographic approach.

In the period after Columbus, other explorers and European invaders provided additional accounts of New World drug use. Amerigo Vespucci, for example, first described coca chewing in South America at the turn of the 16th century (Aldrich and Barker 1976). Drug use among the Aztecs, a behavior observed and recorded by a number of Spanish colonialists and clerics, included several substances. Jimsonweed (*Datura inoxia*) was used by them for both religious and medicinal purposes. Healers consumed jimsonweed mixed with peyote to determine appropriate treatments for their patients. Patients also were given the drug for some ailments. In addition,

the plant was one of the ingredients in a salve that was rubbed on the Aztec priests who performed human sacrifices (Gayton 1928). Some descriptive accounts of colonial drug use are also available. Opler (1970), for example, reproduced a portrait written by Robert Beverly of an encounter in 1676 with jimsonweed by British troops sent to put down Bacon's Rebellion.

Feldman and Aldrich (1990) credit Thomas De Quincey as being the first writer to produce a book-length work that could fairly be called a premodern "drug ethnography." Although an adventurer and not a trained social scientist, De Quincey, who spent a number of years living among the urban poor, was a keen observer of the significant upsurge in opium and alcohol use in the working class districts of London during the Industrial Revolution. He also was interested in drug use among prominent individuals, such as the poet Samuel Taylor Coleridge. De Quincey's book *Confessions of An English Opium-Eater* (1995, originally published in 1822), records his personal experiences with and observations of opium use across social classes. Unlike in the East, where it was smoked, the opium users observed by De Quincy drank it in liquid form, a practice that continued until the introduction of the hypodermic needle.

Another astute observer of street drug use in England during this era was Frederick Engels, who recorded his firsthand observations of the city of Manchester in 1844 in his book *The Conditions of the Working Class* (Engels 1993). Engels, who was led through the polluted and heavily crowded backstreets and alleyways of Manchester by his working class Irish girlfriend Mary Burns, was repulsed by the harsh and degraded living conditions of urban poor people and of the social practices, supported by dominant institutions, that sustained inner-city life during the takeoff years of the Industrial Revolution. For example, in a discussion of patent medicines, Engels notes:

One of the most injurious of these patent medicines is a drink prepared with opiates, chiefly laudanum, under the name Godfrey's Cordial. Women who work at home, and have their own and other people's children to take care of, give them this drink to keep them quiet, and, as many believe, to strengthen them. They often begin to give this medicine to newly born children, and continue, without knowing the effects of this "heart's-ease," until the children die (Engels 1993).

Engels (1993) saw in the use of substances by the urban working class, a population that he believed to be in need of “forgetting for an hour or two the wretchedness and burden of life,” an example of what he termed “social murder,” which was intended to convey somewhat the same meaning as the contemporary use of “structural violence” (Farmer et al. 1996).

As this review of premodern drug studies suggests, over the centuries a scattered array of nonscientific descriptive accounts of drug use have accumulated. For the most part, these texts are a consequence of the curiosity of the writer (or his or her employer) about unfamiliar and often (from the observer’s perspective) exotic behaviors, some among newly encountered peoples and others among hidden populations closer to home. In a few cases, such as that of Engels, the observations were guided by a theoretical perspective, but usually they were not. Like much descriptive ethnography, they served primarily to document the rich diversity of life patterns found across place and time, affirming that drug use is an ancient, varied, widespread, and often socially integrated practice. Inherent in such description is the insight that drug use should not be conceived as an example (nor, as is often the case, as the epitome) of social deviance (Waterston 1993); rather, it must be understood in social context.

## **ETHNOGRAPHY REALIZED: MODERNIST FIELD STUDIES OF DRUG USE**

The era of modern ethnographic drug research, consisting of systematic field observation and careful description of actual behaviors in social context, began in the late 1930s with two seminal studies. Anthropologists often consider LaBarre’s (1989, originally published in 1938) field examination of ritual peyote use among Native Americans to be the first full-fledged drug study by a professional ethnographer. Sociologists, by contrast, point to Dai’s (1937) study of opium addicts in Chicago as the grandfather of modern drug ethnographies. Together, these two studies constitute the starting points of modern field research on drug use. Since then, anthropologists and sociologists have produced a long series of studies of drug use, primarily carried out in major U.S. urban settings like New York, Chicago, and Philadelphia (but including a growing range of research sites over time), using observation or open-ended, indepth interviewing within a quasi-ethnographic or full ethnographic approach.

In 1935 LaBarre began research on peyote use among the Kiowa Indians for his doctoral dissertation. Over the next year, he conducted field observations of ritual peyote consumption with 15 different Native American tribes. The first edition of the book (1938) based on his dissertation research, *The Peyote Cult* (LaBarre 1989), came out during a period of growing anthropological interest in Native American incorporation of the small hallucinogenic cactus into revitalization rituals (Opler 1938; Schultes 1938). True to the anthropological orientation to substance use, LaBarre's work on peyote emphasized the cultural context of consumption. In the case of Native American peyote use, this was not a difficult task given its highly ritualized and richly symbolic treatment. Less ritualized and socially marginal drug use, such as that found among urban poor people, tended not to attract anthropological attention during this era. Thus, Bennett and Cook (1990, p. 231) could conclude that "as of the early 1970s, anthropology had not yet developed an explicit drug research tradition, especially with respect to abuse of drugs."

Sociology, by contrast, did develop an explicit drug research tradition, and its origin is found in the work of Dai (1937, p. 645), who was concerned with understanding addicts "as a group and the world they live in." This is the tradition of "drug use as social deviance," a trend that began in the approach to community-based social research known as the Chicago School. This orientation, developed by Park, viewed modern urban dwelling as a new way of life that was best understood through direct field observation of the numerous small social settings (like particular worksites or neighborhoods) and subgroups (e.g., street gangs, petty thieves, musicians) that make up the urban whole. Methodologically, the Chicago School utilized a mixed approach that included "seeking out the [target group] member's perspective . . . observing human group life naturalistically . . . and being in situ" (Adler 1990, p. 96), strategies that form important components of the ethnographic method. As Moore (1979, p. 8) stresses, the Chicago fieldwork tradition "virtually mandated that major consideration be given to the point of view of the communities and the people under study," a sentiment shared with the Malinowskian research tradition in anthropology. Moreover, Park saw the city as a stressful environment that produces a breakdown of social bonds, disorganization, individual isolation, depersonalization, and deviant behavior. In short, life in cities is pathological, and the behavior of urban dwellers, especially inner-city populations, reflects the urban

social crisis. Drug abuse, consequently, is seen as a direct expression of the deeply damaging effects of urban life.

In his book *Opium Addiction in Chicago*, Dai (1937) reported findings from his fieldwork and life-history interviewing with two populations: individuals with an iatrogenic addiction to morphine as a result of medical treatment and those who acquired their addiction on the street through their involvement with other drug users. This division is important because of the reigning view of addiction during this period. As Goode observes, in the late 19th century, in the aftermath of the Civil War and the widespread use of morphine during battlefield surgeries, “The drug addict was viewed as a helpless victim, an unfortunate sick person in need of medical attention . . . But by the 1920s the public image of the addict had become that of a criminal, a willful degenerate, a hedonistic thrill-seeker in need of imprisonment and stiff punishment” (Goode 1993, pp. 217-218).

Congressional passage of the Harrison Act in 1914, which prohibited over-the-counter sale of narcotics, was one of the factors shaping the public (and researcher) reconstruction of the drug addict image. By 1925 there were more than 10,000 arrests on Federal drug charges (Lindesmith 1965). Through media and other reports of these arrests, the “link between addiction and crime—the view that the addict was by definition a criminal—was forged” (Goode 1993, p. 221).

However, another factor also shaped the public image of the drug addict during this era. By the 1930s African-American drug addiction was becoming increasingly common. Dai (1937) reported that in Chicago during the years 1928-1934, African Americans constituted 6.9 percent of the population but accounted for 17.3 percent of individuals addicted to drugs (22 percent of whom were unemployed). This pattern continued in subsequent years, not only in Chicago but also in other northern, midwestern and western urban centers in the United States as well. A number of factors contributed to spiraling rates of drug use and addiction among African Americans. For the most part, African Americans were relatively recent arrivals in the city, having migrated northward beginning in the early 1900s in one of the largest population transitions in U.S. history. In places like Chicago—which has been called the most segregated city in America—they encountered racism, social isolation, family disruption, broad-based discrimination, and urban poverty (which experientially was considerably more

oppressive than the rural poverty most had known in the South prior to the migration). In addition, during Prohibition, African-American neighborhoods “became the place where whites practiced their vices” (James and Johnson 1997, p. 16). During this period, black-owned jazz clubs, afterhours spots, houses of prostitution, gambling halls, and dance clubs emerged as important social centers for the growing African-American urban population. Whites, anxious for excitement and an escape from the depressive economic situation, flocked into the inner city “to hear African American music, to party, to patronize houses of prostitution, and to gamble” (James and Johnson 1997, p. 17). Among those who patronized the urban clubs were African-American soldiers who returned from the First World War and exposure to drug use overseas, as well as individuals with a more pecuniary interest in drug use. These associations, and the racist sentiments that fueled them, contributed to the demonization of the addict as the ultimate deviant, the embodiment of things strange and threatening to proper society.

In this context, Dai launched his field study of opium use, bringing to the task a psychoanalytic approach to behavior. Although an ethnographic methodology, which by design is geared to the study of social process and performance in context and may seem ill suited to a highly individualized perspective like psychoanalysis, the combination has guided a number of researchers (see LeVine 1971). As Feldman and Aldrich (1990, p. 18) note, given Dai’s orientation, it is not surprising to find that his observations were “cast in terms like ‘infantile’ personalities, excessive dependence on other, and a tendency to withdraw or escape from social responsibility.” Use of these constructs was further reinforced through the recruitment of many respondents through the Psychopathic Hospital in Chicago.

In addition, as noted above, Dai helped usher in the social deviance approach to drug studies. This understanding, suggested although never fully developed in Dai’s work, depicts the drug user as caught up in “an all-consuming life-style” (Waterston 1993) or total way of life (Bell 1971; Inciardi 1986). Some researchers have referred to the existence of a “deviance syndrome” among impoverished inner-city drug users (McGee and Newcomb 1992). For example, Bineau (1989) asserted that regular intravenous drug use “quickly leads to a lifestyle often associated with social marginality, a lifestyle where risk-taking and danger play central roles.” Thus, Dai (1937, p. 136), in discussing the link between drug use and prostitution, writes the following: “That the pimp in his attempt to entice a girl to his service

not seldom ‘dopes’ her and makes her an addict . . . .” Once addicted, from the perspective of the deviance model, drug users come to view “themselves as culturally and socially detached from the life style and everyday preoccupations of members of the conventional world” (Retig et al. 1977, p. 244). According to the deviance model, the issue is not just drugs and their pharmacological effects. Rather, the model asserts that “addicts become addicted not only to drugs but to a way of life” (Lindesmith et al. 1999, p. 571).

In these examples, as Hills (1979, pp. 12-13) observes, “the label ‘addict’ . . . typically conjures up a picture of a strung-out, dirty, furtive, lower-class street junkie—but does not readily bring to mind the millions of middle-class alcohol- and barbiturate-addicted housewives.” Consequently, later writers have questioned the deviance model, arguing that it “leads to an exaggerated picture of [drug] users’ lives, as well as an overstatement of differences between users and nonusers . . . ” (Waterston 1993, pp. 14-15).

One of the researchers, a social psychologist named Lindesmith who worked with Dai, helping him select and recruit his sample, went on to make his own contribution to ethnographic drug research as well as to the broader drug use and addiction field. As Feldman and Aldrich (1990, p. 18) point out, Lindesmith “used qualitative interviewing techniques to develop definitions of addiction—probably the first in the world derived from ethnographic research”—and during the post-World War II years used this work to help move professional thinking about addiction toward a medical model. Lindesmith (1947, 1968) proposed a social theory of addiction. In doing so, he rejected explanations of addiction that were based solely on the alleged pharmacological and dependence-producing characteristics of drugs, arguing instead that when drug users seek to stop using drugs, they often are attracted back to familiar social settings, relationships, and behavioral patterns. Employing an emic approach to the problem of addiction, Lindesmith argued that a definition of this phenomenon “must come from those ‘addicted’ rather than those who have never used opiates, and that definition should reflect common experiences of this population” (Knipe 1995, p. 91).

In his interviews with heroin users, Lindesmith found a range of experiences associated with the injection of heroin, with some users reporting pleasurable responses and others indicating minimal pleasure. All respondents, however, affirmed that continued use

protected them from the painful discomfort of withdrawal (Lindesmith 1968). Thus, addiction, in Lindesmith's view, is not simply a physical need for a particular drug but also a body of shared cultural knowledge about the drug and its effects. In seeking to understand the nature of addiction, Lindesmith's work reflects the primary question driving the work of drug researchers of this era: Why do people use drugs?

With some of the key questions about the nature of addiction settled—at least for the time being—the focus of ethnographic drug research shifted in the years after Lindesmith began to publish his research. However, the body of ethnographic research on drug use that was beginning to develop during the 1930s came to a sudden halt with the Second World War. Not only did the war block the flow of many drugs into the United States—leading to a significant drop in the frequency of drug use and the number of users—it also pulled potential drug researchers out of the field and into the war effort. Ethnographic research on drug use did not begin to gather momentum again until the late 1950s and early 1960s.

In the immediate post-World War II years, a period during which heroin began to flow back into the United States in increasing quantities and the number of inner-city drug users began to rise quickly, one must turn to a number of autobiographies of drug users to gain a socially contextualized and quasi-ethnographic account of drug use during this period. Several books, including *The Autobiography of Malcolm X* (1989), *Manchild in the Promised Land* (Brown 1965), *Down These Mean Streets* (Thomas 1967), and *Manny: A Criminal-Addict's Story* (Rettig et al. 1977), are particularly important resources in this regard.

Prior to his conversion to Islam and his subsequent emergence as a charismatic and militant African-American leader, Malcolm X spent a number of years, beginning during the Second World War, as a drug dealer. His specialty was marijuana, which he rolled into cigarettes (“reefers”) and sold to musicians in Harlem. For a while, he even went on the road carrying a jar filled with marijuana “sticks” for sale to musicians in various east coast cities. This association between the arts and drug use helped create a street image of the drug user as a glamorous role worthy of emulation: “In every band, at least half of the musicians smoked reefers . . . I kept turning over my profit, increasing my supplies, and I sold reefers like a wild man. I scarcely slept; I was everywhere musicians congregated” (Malcolm X 1965, p. 99).

Before long, Malcolm X caught the eye of the police. Under increasingly intense police pressure, he gave up selling marijuana and turned to other hustles. But he continued to smoke marijuana and developed a dependence on cocaine. Supporting himself and his addiction through burglary, he avoided worrying about getting caught by sniffing more cocaine and smoking marijuana. However, at age 20, in February 1946, Malcolm X was arrested for robbery, convicted, and sentenced to 8 to 10 years in prison. While he initially continued to use whatever mind-altering substances that he could get his hands on in prison, with his conversion to Islam he forswore all drug use.

As a result, Malcolm X was never swallowed up by the postwar heroin boom in New York City. For Claude Brown, a few years younger than Malcolm X, by age 13 heroin was such a powerful attractant that he could hardly contain his desire to try it. Like Malcolm X, Brown was introduced to drug use by his friends, especially a group of older boys whom he greatly admired. They first taught him to use marijuana. When they moved on to heroin, which among other names was called “horse” at that time, he intensely wanted to join them. For several months during 1950 all he could think about was his desire for heroin:

Horse was a new thing, not only in our neighborhood but in Brooklyn, the Bronx, and everyplace I went, uptown and downtown. It was like horse had just taken over. Everybody was talking about it. All the hip people were using it and snorting it and getting this new high . . . I had been smoking reefers and had gotten high a lot of times, but I had the feeling that this horse was out of this world (Brown 1965, p. 103).

Ultimately, Brown got his chance to try heroin. Although some heroin users report that their first exposure to the drug is extremely pleasurable, like love at first sight, leading to a long-term chase intended to relive the initial experience, Brown had a different reaction. After a few moments of euphoria: “My head seemed to stretch, and I thought my brain was going to burst . . . I’d never felt this way before in my life . . . My guts felt like they were going to come out . . . And I said, O Lawd, if you’ll just give me one more chance, one more chance, I’ll never get high again” (Brown 1965, p. 111).

Brown continued to use marijuana, but he never again tried heroin. He did, however, begin to deal marijuana and cocaine. Then he was

robbed at gun point by a heroin addict. Before Brown could find the addict who robbed him, the man was shot several times by the police, which “took the heat off” of Brown (1965, p. 178) to get revenge. As a result, however, Brown gave up drug dealing and was able to escape the emergent heroin epidemic of the post-World War II era in Harlem. Many of his friends were not so lucky:

A lot of younger cats who were taking numbers would start using drugs, and then they would start (\*\*\*\*\*) with people's money . . . People started to get shot and things like that over their money because cats needed it to get drugs. A lot of junkies started sticking up the numbers writers and sticking up the controllers . . . Peddling drugs had become a popular vocation in Harlem . . . (Brown 1965, p. 191).

During these years, in nearby Spanish Harlem, Piri Thomas, a boy of mixed Puerto Rican and African-American heritage, was a member of the younger postwar generation that was coming of age and coming into contact with drugs. He recalled one of his earliest encounters with marijuana at age 13. While drinking whiskey with several friends, one of them produced a “stick” of marijuana and asked if he would like some: “I put it to my lips and began to hiss my reserve away. It was going, going, going. I was gonna get a gone high. I inhaled. I held my nose, stopped up my mouth. I was gonna get a gone high . . . a gone high . . . a gone high . . . and then the stick was gone, burnt to a little bit of a roach” (Thomas 1967, p. 58).

Like Malcolm X and Brown, within a few years Thomas was selling marijuana. But his initial reaction to heroin, which was becoming widely used, was negative. At age 16 watching friends use heroin he noted: “I smoked marijuana . . . but I was down on [harder] drugs. I had seen the young-old cats that dope [heroin] had messed up, the poor chumps who would try and hustle a buck or steal anything that would bring the price of a cap . . . to drive that mean devil away for awhile” (Thomas 1967, p. 109).

But Thomas’ resolve to avoid heroin was overcome by his need to prove he was not a “punk.” When a peer, Alfredo, presented him with a dollar cap of heroin and a folded matchbook to use in sniffing the powder, Thomas felt compelled to prove himself a worthy companion: “All for the feeling of belonging, for the price of being called ‘one of us’” (Thomas 1967, p. 204). The ability of heroin to take away all pain, misery, and rejection made the drug instantly

appealing to Thomas: “All your troubles become a bunch of bleary blurred memories . . .” (Thomas 1967, p. 200). Before long, Thomas’ life came to center on the drug. He’d “go to bed thinking about [heroin] and wake up in the morning thinking about it” (Thomas 1967, p. 207).

With a habit to support, Thomas had to develop a way to make money. An inner-city youth with no job skills and unlikely, as a black Puerto Rican, to find legitimate employment even if he had them, he felt he had only two options: stealing or selling drugs. He chose the drug trade. Like X, Thomas wound up in prison, where his habit switched to benzedrine, phenobarbital, alcohol, strained shellac, and whatever else the inmates could get their hands on that could take them away from the stone-cold realities of prison life.

The final autobiographical work of note is the life history of Manual Torres. In most ways, Torres’ life story is the same as those already presented. He had been a gang member from his early teens during the 1950s, and he tried heroin under circumstances not very different from those of Brown. Like Brown, Torres’ first experience with heroin was unpleasant. But his addict role model was his uncle who encouraged him to try heroin again: “So I snort again and hey, it’s like the (\*\*\*\*) really hit the fan . . . you can’t describe it. All the colors of Times Square tumble right over your forehead and explode in your eyeballs like a million, jillion shooting stars . . . Everything’s beautiful, and it’s like nothing’s happening baby but clear, crisp light . . . (Rettig et al. 1977, pp. 33-34).

Before long, Torres was injecting heroin four times a day, not to achieve a rush, but “just to maintain” (Rettig et al. 1977, pp. 33). He began to “boost” (shoplift) to support his drug habit and then turned to armed robbery, which led to arrest and imprisonment. Many years later, in reflecting on his life, Torres emphasized the politicoeconomic origin of involvement with drugs among inner-city youth. Responding to a statement about Durkheim’s theory that the social role of criminals is to set the boundaries of acceptable behavior for the rest of society, Torres stated: “That’s fine if you’re on the right side of the tracks. But what if you are locked into the streets and locked out of the jobs because of your background or your dope habit? . . . Personal breakdowns are an aspect of social breakdowns” (Rettig et al. 1977, p. 175).

These four autobiographical accounts and related material (e.g., Burroughs 1985; Courtwright et al. 1989) clearly reveal the development of the postwar drug scene in the inner city. Building on the image of the “cool” marijuana user of the depression and war years, the close of the Second World War ushered in a period of significant increase in heroin use and heroin addiction. The street addict became a common sight on inner-city streets, as each new generation of youth, boys and girls alike, sought to prove themselves to their peers by adopting the valued image of a fearless drug adventurer. Other options and role models were few, and none seemed to offer as much opportunity to impoverished youth who felt they had to prove their worth to their peers or face rejection in the one arena—the streets—that offered any potential life validation. However, in the wake of the heroin “plague,” Harlem and other U.S. inner cities changed. The sense of community that somehow had managed to survive the migration of African Americans from the South and Puerto Ricans from the island, the grinding poverty they encountered in their new northern and midwestern homes, and the fierce racial discrimination that undercut self-esteem and self-worth now fell victim to widespread drug addiction among impoverished individuals who had nowhere to turn for drug money except robbery, burglary, prostitution, and other crimes against themselves, their families, and their neighbors.

Yet rampant drug use in the inner city after World War II did not attract much attention or real concern from the dominant society or its social scientists, except to the degree that drug users were mentioned as either psychologically damaged or as criminal deviants in need of harsh punishment. Often in the social and behavioral science literature, drug addicts were portrayed as being “either psychotic or neurotic casualties” (Inciardi 1991, p. 30). Typical was the description of Chein and coworkers, who argued that

... all addicts suffer from ... personality disorders .... They are not able to enter into prolonged, close, friendly relationships with ... peers; they have difficulty assuming a masculine role; they are frequently overcome by a sense of futility, expectations of failure, and general depression; they are easily frustrated and made anxious, and they find frustrations and anxiety intolerable (Chein et al. 1964, p. 30).

Policymakers’ main interest in drug users was because of their involvement in crime and because they were assumed to come

primarily from ethnic minority communities. Whereas the typical 19th-century opium addict was “middle-aged, female, rural, middle-class and white” (Conrad and Schneider 1990, p. 116), as the typical opium addict at mid-20th century became increasingly a “young, lower-class black male . . . moral hostility increased proportionately” (Conrad and Schneider 1990, p. 127). To strengthen the criminal justice approach to addiction, the congressional Kefauver Committee on Crime held a series of televised hearings that drew public attention to the role of drug use in criminal behavior. Meanwhile, a number of widely read popular magazines published alarmist articles about the rising peril of drug use. In light of the reigning McCarthyite beliefs of this era, drug use soon was linked not only to property crimes but also to communism.

In the latter part of the 1950s, however, an alternative to this reigning view of drug users began to appear. Its source was the qualitative, interactive study of drug users. One of the first qualitative studies to mark this turning point was conducted by Finestone (1957), a sociologist, among African Americans in Chicago. Although not based on ethnographic research *per se*, Finestone’s office-based qualitative interviews with approximately 50 African-American heroin addicts helped focus social scientific attention on the existence of a world view and a subculture among drug addicts. Finestone sought to describe the prototypical African-American drug user roles (the “cat”), the often illegal income-generating activities needed to sustain drug use (the “hustle”), and the use of drugs (the “kick”). As Feldman and Aldrich (1990, p. 19) note, Finestone’s drug studies began a shift in emphasis away “from asking why people used drugs [and toward] asking how they went about getting involved in drug use and how they remained involved . . . [E]thnographers began to find their search for etiological influences in the social world rather than the internal [psychological] world of experimenters.” In other words, as a result of open-ended qualitative interviewing of drug users, there began a move away from psychoanalytic and psychiatric thinking, as seen in the work of researchers like Dai and Chein, toward a more sociocultural and meaning-centered approach to drug use.

Even the title of Finestone’s (1957) most important article, “Cats, Kicks, and Color,” reflects this shift toward a concern with the drug user’s experience of “the life,” the details of insider speech, and the contours of the subcultures of drug users. The change is further evidenced in two of the other seminal articles that ushered in the new

orientation: “The World of the Righteous Dope Fiend” (Sutter 1966), based on 3 years of fieldwork with addicts and controls in Oakland, CA, and, especially, the classic “Taking Care of Business” (Preble and Casey 1969), based on research in New York. The primary goal of much of this literature was the holistic description of the people for whom drug use was said to be the central organizing mechanism of their lives. For example, to counter simplistic stereotypes of drug users, Preble and Casey argued:

Their behavior is anything but an escape . . . They are actively engaged in meaningful activities and relationships seven days a week. The brief moments of euphoria after each administration of a small amount of heroin constitute a small fraction of their daily lives. The rest of the time they are actively, aggressively pursuing a career that is exacting, challenging, adventurous, and rewarding. They are always on the move and must be alert, flexible, and resourceful (Preble and Casey 1969, p. 2).

In constructing their descriptions, ethnographic researchers of this period tried to understand and represent the world as it was actually seen, lived, and experienced by hardcore drug users. To a large degree, this literature consists of fascinating and detailed accounts of the survival strategies used to sustain a drug-focused lifestyle, the underground economy of drug acquisition, processes of socialization into drug use social networks, social settings that make up drug users’ social environments, folk systems used to classify drug users by their social status in the subculture, and the special argot or language system developed to communicate issues of concern to drug users (and to hide information from outsiders, including the police). In short, the ethnographic literature on drug use from the 1960s onward emphasized the assertion that the lives of drug users are not without considerable cultural order and socially constructed meaning. Drug getting and use as social activities provide the framework for this order. As Preble and Casey comment:

The heroin user walks with a fast purposeful stride, as if he is late for an important appointment—indeed, he is. He is hustling (robbing and stealing), trying to sell stolen goods, avoiding the police, looking for a heroin dealer with a good bag (the street unit of heroin), coming back from copping (buying heroin), looking for a safe place to take the drug, or looking for someone who beat (cheated) him—among other things. He is, in short, taking care of business, a phrase which is so common with heroin users that

they use it in response to words of greeting, such as “how you doing?” and “what’s happening?” (Preble and Casey 1969, pp. 2-3).

In addition to structural behaviors and social meaning, researchers identified a set of distinctive values. For example, Sutter (1966, p. 195) noted that within the subculture “[p]restige in the hierarchy of a dope fiend’s world is allocated by the size of a person’s habit and his success as a hustler.” Heroin users at the peak of the drug status hierarchy were observed by Sutter to work hard to maintain their position and their lifestyle. More broadly, on the street, Feldman found that heroin users were seen as having

positive qualities of creativity, daring and resourcefulness that provide the impetus for the top level solid guys (persons of established status) to rise to the top of the street hierarchy . . . Their use of heroin solidifies a view of them as bold, reckless, criminally defiant—all praiseworthy qualities from a street perspective (Feldman 1973, p. 38).

These accounts, shaped by an emergent “drug use as subculture” paradigm (Johnson 1980, pp. 110-119), took researchers a long way from earlier conceptions of drug users. As summarized by Friedman and coworkers with reference to injection drug users (IDUs):

In contrast to views that see IV drug use as simply a matter of individual pathology, it is more fruitful to describe IV drug users as constituting a “subculture” as this term has been used within sociological and anthropological research . . . This calls our attention to the structured sets of values, roles, and status allocations that exist among IV drug users . . . (Friedman et al. 1986, p. 385).

In short, ethnographers of drug use working in the period just before the appearance of AIDS tried to show that even under difficult circumstances—or more precisely, because of difficult circumstances—a subculture can emerge that is as meaningful and dear to its participants as it is alien and repugnant to “outsiders.” Furthermore, they attempted to counter earlier images of the drug user framed by the paradigms of psychopathology and the sociology of criminal deviance. In so doing, however, they often turned their attention away from the wider social context that fosters drug use and the intense social suffering it often expresses and instead emphasized the

microsocial world of the drug users in holistic culturalist terms (Waterston 1993).

Components of the drug-use-as-subculture tradition were carried on by a second generation of researchers whose drug research careers began generally just before but extended into the era of the AIDS epidemic. Several seminal ethnographic studies were produced by this second generation, including Agar's *Ripping and Running* (1973), Waldorf's *Careers in Dope* (1973), Hanson and colleagues' *Life With Heroin: Voices from the Inner City* (1985), the volume by Johnson and coworkers (including Preble) tellingly titled *Taking Care of Business: The Economics of Crime and Heroin Abusers* (1985), and Feldman's *Angel Dust: An Ethnographic Study* (1979). Each of these studies, primarily written in a normal science vogue from a "drug user lifestyle perspective," made important ethnographic contributions to the drug field. In so doing, however, as is common in scientific research, their findings called into question aspects of their guiding paradigm.

Agar's study, a "formal" or ethnosemantic ethnography of the categories of cognitive organization of everyday events in the lives of heroin addicts, was based on 2 years of fieldwork with patients at the National Institute of Mental Health Clinical Research Center in Lexington, KY, a Federal drug treatment hospital. He describes his approach as follows:

I would spend time hanging around in the patients' areas of the institution, listening and trying to learn how they viewed the world by attending to how they talked about it . . . After doing this for several months, and after conducting several informal interviews and assembling a dictionary of slang, I began to worry about being more systematic. So I worked up three interlinked methods to help me display my understanding of the junkie world view (Agar 1980, pp. 137-138).

These methods, which were suggested by a wider anthropological turn toward viewing culture as a shared cognitive template for enacting socially appropriate behavior, were (1) the simulated situation (tape-recording drug user enactments or simulations of real street drug-related behaviors like "copping" [buying] drugs and "getting off" [using drugs]), (2) frame elicitation (a fill-in-the-blank approach in which the study participant was handed a card or read a statement about some aspect of street drug life and asked to use his

or her experience to complete the sentence), and (3) the hypothetical situation (in which the participant was told about a life situation drawn from prior data collection and asked to select from possible courses of action). On the basis of these methods (both formal and informal), Agar was able to construct an “experience-near” account of key scenes, concepts, relationships, artifacts, activities, and experiences that constitute the street drug user’s life. Later, Agar was able to test the validity of some components of his understanding of this lifestyle using street ethnography (Agar 1977) and sociological survey (Agar and Stephens 1975) in New York City.

Another component of Agar’s study was an attempt to understand the lives and behaviors of drug users as patients in drug treatment. In other words, in addition to eliciting information about life on the streets, he also was concerned with the experience of life in an institution. Agar was able to address ethnographically some of the issues he encountered as he learned about staff attitudes and assessments of patients. One of his insights in this regard was that some of the very behaviors (e.g., strong skepticism, constant suspicion, and testing of dependability) that the staff cited as evidence that patients were maladapted and lacked appropriate values, goals, and rules of proper behavior were appropriate to survival on the streets where the threats are multiple and often come in human form.

Using a somewhat different starting point, Waldorf’s (1973) *Careers in Dope* was based on a concept introduced into the Chicago research tradition by Hughes and first applied to drug use by Becker (1953) in his important study of the pathway to becoming a marijuana user and the social contexts and relations that perpetuate drug use. The “career” concept in drug research implies that, similar to a professional in a field of employment (as in drug research), it is possible to identify somewhat standardized stages and transitions in the processual development of a drug user’s life. The heroin user’s career in the inner city, argues Waldorf, begins early in life:

Heroin is seemingly everywhere in Black and Puerto Rican ghettos and young people are aware of it from an early age. They know of heroin and addicts through close scrutiny—they see the endless trade of money for white power; they see the user nodding on the front stoop; they watch him “get off” in the communal bathroom . . . they see this theft of the family TV set (Waldorf 1973, p. 6).

Waldorf noted that large numbers of youth from disadvantaged households have few experiences of legitimate employment on which to build a “straight” lifestyle. Instead, they develop “elaborate deviant identities and ideologies” (Waldorf et al. 1992, p. 220) centered around drug use. Waldorf examined the survival strategies and established subcultural roles in the drug use world on which these alternative identities and ideologies are based. He observed that street drug users had to spend many hours each day planning and carrying out some form of income-generating hustle. Drug dealing, he noted, was considered one of the better hustles available to street drug users, although the primary “career path” open to them in the drug trade was as low-level street “jugglers” who sold small quantities of drugs to fellow addicts.

At the terminal end of the dope career, Waldorf (Waldorf and Biernacki 1981) examined untreated natural recovery from heroin addiction, a transition out of drug use, or “retirement” in the career model, that many have assumed is not possible or at least extremely rare. He found that many former heroin users “drifted out” of drug use without significant problems because they had never been highly committed to the drug or the drug user lifestyle. Waldorf also led one of the first modern ethnographic studies of cocaine use (Waldorf et al. 1977) and later used an ethnographic approach to study longer term careers among cocaine users. One of the important findings of the later study was the identification of a protracted career path among some cocaine users that involves continuous controlled consumption:

Cocaine is an alluring drug. It has many uses. It has become widely available. For all of these reasons users often escalate their doses. But approximately half of our subjects sustained a controlled use pattern for periods ranging from a year or two to a decade. Our definition of “controlled use” is a pattern in which users do not ingest more than they want to and which does not result in any dysfunction in the roles and responsibilities of daily life (Waldorf et al. 1992, p. 265).

The Heroin Lifestyle Study (HLS) that led to the writing of *Life With Heroin: Voices from the Inner City* (Hanson et al. 1985) was carried out in the inner-city areas of Chicago, New York, Washington, DC, and Philadelphia. Study participants consisted of 124 African-American men. All were regular heroin users, and most had “never received or wanted any form of drug treatment” (Hanson et al. 1985,

p. 1). This disinclination to enter treatment was a primary focus of the study. Specifically, the study was designed to “accurately pass on the rich, descriptive firsthand accounts of the daily lives of Black heroin users . . . and second, to search for and analyze emergent patterns which reveal the complex social and psychological mosaic that comprises the contemporary Black inner-city heroin lifestyle” (Hanson et al. 1985, p. 2). Ironically, one of the important findings of the study concerns the validity of assuming that there is a distinctive heroin lifestyle that is separate from the basic lifestyle pattern of the surrounding inner-city community. As two members of the HLS research team note:

An unexpected finding is that the HLS men live rather structured lives in which successive daily time periods are spent engaging in a variety of fairly predictable and even conventional activities. Like men in straight society, they arise early in order to spend many of their waking hours “on the job”—but in their case, this usually means hustling in pursuit of the wherewithal to maintain their once-a-day, relatively controlled heroin habits (Bovelle and Taylor 1985, pp. 175-176).

It was the “pursuit of normalcy” (under conditions of marked social inequality and lack of opportunity) rather than escape or exhilaration that was found to drive the continued use of heroin among study participants. Also noteworthy was the control participants exercised over their drug habits, a refutation of the common assertion that regular heroin users “have an insatiable and uncontrollable appetite for heroin and that they therefore shoot up as many times as possible each day” (Bovelle and Taylor 1985, p. 177). In short, as Waldorf and coworkers had done among cocaine users, the HLS identified a stratum of heroin users that did not fit reigning stereotypes about this population or ethnographic descriptions of other inner-city heroin users, revealing both the changing nature of the heroin scene and a notable heterogeneity of drug-using populations.

One of the insights of the Preble and Casey (1969) study was that street drug users are key players in a street economy that involves the redistribution of goods that are stolen from stores, warehouses, or other locations and sold on the streets or to local stores and restaurants at discount prices. Bourgois (1996, p. 3) credits this “enormous, uncensored, untaxed underground economy” as one of the main factors that allows poor inner-city residents to avoid rampant malnutrition and high rates of morbidity and mortality in

oppressed inner-city areas. Ethnographically exploring the drug user role in the underground economy was the focus of the research presented by Johnson and colleagues (1985) in *Taking Care of Business: The Economics of Crime and Heroin Abusers*. Working from field research stations set up in east Harlem (Spanish Harlem) and central Harlem in New York City, the project staff, composed of researchers and recovering drug addicts, recruited 201 active drug users and interviewed them concerning income-generating and spending patterns. Each participant was interviewed for 5 consecutive days and then once a week over the next month (with additional followup interviews at the east Harlem site). Specific issues of concern were legal and illegal sources of income, types of illegal activities, arrest record, and daily expense information. The study produced a massive amount of data, which was synthesized by Johnson and his team to clarify the size, scope, and character of the underground economy and its interrelationship with the aboveground economy. Johnson and coworkers performed various calculations to assess the economic impact of the drug-use-driven informal economy. Unlike other researchers who have sought to demonstrate only negative effects of drug-related crime, benefits to the community were identified. For example, they assessed the economic impact involved in a drug user stealing a \$400 color television from someone's home and selling it to a merchant (who, in turn, sells it to a customer) for money to use in buying drugs. According to Johnson and coworkers (1985, p. 117): "One person—the individual victim—had a substantial loss, but that loss was offset by the direct and immediate gains to four other parties: the burglar, the purchaser of the stolen television, the retail merchant, and the drug seller."

Central to this argument is the idea that, even when an item like a TV is stolen, it does not mean that it disappears from the economy; it is merely redistributed (even if most of the monetary profits of drug sales are extracted rather than recirculated in poor neighborhoods). This study revealed how the underground and the aboveground economies are, in fact, one economy.

*Angel Dust: An Ethnographic Study of Phencyclidine Users* (Feldman 1979) was a particularly important contribution for a number of reasons. The edited volume was a product of a collaborative, multisite ethnographic study carried out simultaneously in four cities (Miami, Philadelphia, Chicago, and Seattle) using a common research protocol. The study was initiated because of reports that phencyclidine (PCP) (also known as angel dust), an animal

tranquilizer with hallucinogenic properties, was becoming popular among some youth as a regularly consumed psychoactive drug. However, little was known about recreational use of PCP. Agar describes the origin and evolution of the study in the following terms:

A NIDA staff member with ethnographic tendencies (he had been a street worker in New York) decided to try an ethnographic study. He asked that a small team of ethnographers be assembled to get some preliminary feel for the situation . . . [F]our ethnographers were selected who had done good ethnography with drug users in the past. Further, because of their ongoing work, they all had rapport so that they could begin work immediately . . . The group met for 2 days to work out a strategy for doing the ethnographies. Informal interviews were to be the focus. In addition, the group came up with a four-page guide to specific items of information that would be easy to get from each informant (Agar 1980, p. 200).

The study found that PCP had entered youth drug networks in all four target cities in 1973, increased in popularity through 1974, and begun to lose its appeal the following year (although it never completely disappeared from the youth drug scene and continues to have periods of renewed popularity [Holland et al. 1998]). An examination of the National Institute on Drug Abuse's (NIDA) annual national survey of drug use among high school seniors (Monitoring the Future Study) for the mid-1970s (Johnston et al. 1993), however, did not include findings on PCP use. As Feldman and Aldrich (1990, p. 22) remark, "the PCP phenomenon entered the world of youth and diminished without the national data system ever identifying it." When questions about PCP were finally added to the Monitoring the Future Study in 1979, lifetime prevalence for use among 12th graders was found to be 2.4 percent (falling over the years to 1.4 percent by 1991) (Johnston et al. 1993).

The study also found that exclusive PCP use was rare and that its greatest appeal was among especially restless youth who found life to be generally boring and uninteresting. The participants in the study appeared to be familiar with the drug's effects and how to modulate them by controlling dosage levels. Of special concern to regular PCP users was a state they referred to as "burnout," in which the user exhibits memory loss and incoherent thoughts. Cutting back on consumption of PCP emerged as the folk strategy for controlling burnout.

One consequence of the PCP study was the realization that ethnography, a method commonly seen as a requiring a protracted period of rapport building and ever more penetrative data collection, was found to be especially useful for the rapid assessment of emergent drug trends. As Wiebel, who carried out the Chicago arm of the four-city PCP study, has noted:

Generally speaking there appear to be two factors that contribute to the importance of qualitative methodologies in the field of substance abuse research. First, continually evolving patterns and trends of substance abuse . . . foster a fluid situation in which emergent and novel phenomena are integral facets of today's drug scene . . . When attempting to construct meaningful data collection instruments for drug-related research, the researcher must gain sufficient *a priori* familiarity with the topic to frame appropriate, meaningful questions. Such knowledge is the province and product of qualitative methodologies . . . The second factor confirming the value of qualitative methods in the substance abuse field relates more to the types of information required of research . . . Clearly, qualitative research is often the only appropriate means available for gathering sensitive and valid data from otherwise elusive populations of drug abusers (Wiebel 1990, pp. 4-5).

Argues Bourgois (1996, p. 13), the productivity of ethnography in drug use research stems from the fact that the reason drug users are elusive is that they "live on the margins of a society that is hostile to them." By design, ethnography is a methodology that incorporates into its approach to data collection rapport building, self-disclosure, nonjudgmental sensitivity, genuine concern with the insider's perspective and experience, and involvement in the lives of study participants. These features of ethnography provide a basis for the establishment of "relations based on trust . . . [that allow the researcher] to ask provocative personal questions, and expect thoughtful, serious answers" from individuals who have learned to be extremely wary (Bourgois 1996, p. 13). In addition, ethnography not only offers a means of reaching hard-to-reach populations of drug users and providing background information on them that is useful in the construction of good surveys but also, by taking the researcher into the world of the drug user, fosters the development of important hypotheses and research questions and empowers the researcher to produce interpretations of findings that are grounded in the social, cultural, and experiential realities of the study population.

## **ENTER THE POSTMODERN: AIDS AND CONTEMPORARY DRUG USE ETHNOGRAPHY**

Since the late 1980s the ethnography of drug use has been propelled especially by the study of AIDS risk and prevention (although broader social concern about the health and economic tolls of drug abuse is another push factor). The result has been a significant expansion in the quantity of studies (as well as an improvement in ethnographic methods and sampling procedures), especially with regard to the development of fine-grained examinations of the technologies and processes of drug use; the structure of the networks and social relations of drug users; the immediate contexts of street drug consumption; the interrelationship between drug use and a range of health risks; cross-site variation among drug users (including focused investigation of various drug user subgroups such as IDUs, crack users, women, minorities, adolescents, gay men, and lesbians); and the political economic structures, policies, and dominant social practices that foster drug use behaviors. As indicated, much of this new work (which warrants a focused review of its own) has been driven by the recognition that drug use is now the primary source of new HIV infection in the United States, as well as an increasingly important source of HIV infection in many other parts of the world. As a result, research support, primarily from NIDA, for field studies designed to elucidate AIDS (and other health) risks among drug users and their social networks reached new heights and attracted a large number of ethnographers (many without prior histories in the street ethnography of drug use or much awareness of prior fieldwork with street drug users) into the field (Bolton and Orozco 1994).

Ironically, at the very moment that the potential contributions of ethnography to public health were being broadly recognized, the ethnographically oriented social sciences were undergoing intense internal questioning concerning issues of ethnographic authority and representation. For some, the future of ethnography as a legitimate approach to knowledge about the social “other” seemed open to doubt. Though cognizant of the issues and concerns of those voicing this postmodernist critique of ethnography (e.g., Singer 1994, 1995), drug use and AIDS ethnographers came to recognize the need

to suspend or ignore the academic issues surrounding their method in order to respond quickly to a pressing public health problem. Thus the issue of whether ethnography can arrive at the “truth” about people’s everyday ways of life . . . has largely been

waived in favor of the practical goal of achieving the particular kinds of truths needed to establish programs to save people's lives (Kotarba 1990, p. 260).

Researchers who have done so have been able to make useful contributions to AIDS prevention research (e.g., Carlson et al. 1994; Clatts et al. 1995; Connors 1995; Gamella 1996; Kane and Mason 1992; Koester and Hoffer 1994; Ouellet et al. 1991; Schiller et al. 1994; Singer 1997; Sterk-Elifson 1993; Trotter et al. 1995; Weeks et al. 1995). Those who already were steeped in the historical literature on the ethnography of drug use as well were able to move especially quickly in gaining new ethnographic insights about drug use and AIDS risk (e.g., Feldman and Biernacki 1988; Inciardi and Page 1991; Murphy 1987; Page 1990; Waldorf and Murphy 1993; Wiebel 1988). The researchers who spearheaded the critique of ethnography in the 1980s not only have stuck with the methodology but also have come of late to privilege the kind of multisite ethnography (e.g., Marcus 1999) that has been common in the study of drug use since the examination of marijuana use in various Latin American countries (e.g., Carter 1980; Dreher 1982; Page 1982; Rubin and Comitas 1975) and the PCP and HLS studies.

Although at times over the years “[t]he ethnographic approach . . . [has not always been] particularly popular” in the drug research field (Waldorf et al. 1992, p. 14), the approach has continually proven its value in the study of a notably broad array of issues (e.g., Adler 1993; Fields 1984; Goldsmith et al. 1984; Hamid 1990; Hughes 1977; Lambert 1990; Page et al. 1980; Partridge 1973; Ratner 1993; Rosenbaum 1981; Waldorf 1980; Weppner 1977). As summarized by Turner and colleagues (1989, p. 218), ethnographers “are permitted access to otherwise clandestine groups and can describe variations and patterns of behavior in rich detail. They are frequently able to reach the most active drug users and dealers, those who in general are the most criminally involved and the most likely to suffer from a broad spectrum of health problems.”

As Friedman and colleagues (1990, p. 104) assert, “[t]hese contributions show the value of ethnographic and other field research techniques in social and epidemiological investigation, and may well establish these previously derogated techniques as legitimate tools of science.”

Critical to the post-World War II validation of street ethnography was the work of Preble, who spent more than 20 years conducting innovative street research with drug users in Manhattan. As Waterston (1993, p. 26) remarks, Preble's efforts "gave a new legitimacy to participant-observation as a significant research technique among drug researchers, who have since adopted some of Preble's methods as standard procedure." Also, at key points along the way, strategically located sponsors, especially at NIDA, have played critical roles in sanctioning the methodology and promoting Federal funding of ethnographic studies of drug use and related issues, including most especially Eleanor Carroll, George Beschner, and Richard Needle. Carroll strongly supported the funding of ethnographic studies and the inclusion of ethnographers on NIDA grant review panels. Beschner participated directly in field research and helped launch a number of efforts, such as the conference held in Chicago in 1979 that led to the volume *Ethnography: A Research Tool for Policymakers in the Drug and Alcohol Fields* (Atkins and Beschner 1980) and the National AIDS Demonstration Research project (Brown and Beschner 1993), which incorporated ethnography in a nationwide multisite epidemiological study among IDUs and their sex partners. Needle, who is chief of the Community Research Branch at NIDA, continued and expanded the NIDA tradition of support for ethnography through additional multisite studies like the Cooperative Agreement Program for AIDS Community-Based Outreach/Intervention Research (Inciardi and Needle 1998) and the Needle Hygiene Study (Koester 1995; Needle et al. 1994), as well as through the sponsorship of technical reviews and conferences on the ethnography of HIV risk and prevention among drug users (e.g., Lambert et al. 1995).

In the study of hidden behaviors, like illicit drug consumption, "walking" with drug users (into shooting galleries, crack houses, abandoned buildings, homeless shelters, soup kitchens, drug-copping sites, treatment centers, and similar locations where drug users live out their daily lives) has proved to be a productive approach to knowledge generation. Like other research methods, ethnography is a useful strategy for approaching "truth" rather than a guaranteed system for achieving it. As many focus groups conducted with drug users have found, for example, even insiders can sharply disagree about street drug use realities. The most important contribution of ethnography to the study of street drug use is a way of seeing and documenting behaviors in a social context, hearing directly from insiders (in their own words) about their understandings and

experiences, and comprehending the broader social influences on the behaviors of interest.

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